Hispanic Narratives of the Ill or (Dis)abled Woman:

A Feminist Disability Theory Approach

by

April Knupp

A Dissertation Presented in Partial Fulfillment
of the Requirements for the Degree
Doctor of Philosophy

Approved July 2018 by the
Graduate Supervisory Committee:

Carmen Urioste-Azcorra , Chair
Cynthia Tompkins
David William Foster

ARIZONA STATE UNIVERSITY

August 2018

ABSTRACT

Hispanic Narratives of the Ill or Disabled Woman: A Feminist Disability Theory Approach, is a comprehensive study that delves into the topic of the ill or disabled female in the narratives of Hispanic female authors who either have a disability or who have been affected by a chronic or terminal illness, causing debilitation. In order to address this topic, the current thesis investigates disability identity by utilizing feminist disability theory by Kim Q. Hall, Rosemarie Garland-Thomson, and Susan Wendell, amongst others, and at the same time reviews current disability policies in both Latin American and Spanish societies. By providing a critical view of this theme from a feminist standpoint, this study places emphasis on the lived experiences that ill or disabled Hispanic women face, doubly marginalized, not only based on their illness or (dis)ability, but also their gender.

This in depth analysis of *Fruta Podrida* (2007) and *Sangre en el ojo* (2012) by Lina Meruane, *Diario del dolor* (2004) by María Luisa Puga, *Clavícula: (mi clavícula y otros inmensos desajustes* (2017) by Marta Sanz, *Diario de una pasajera* by Ágata Gligo (1997), *Si crees en mí, te sorprenderé* (2014) by Ana Vives, and *The Ladies Gallery: A Memory of Family Secrets* by Irene Vilar provides relevant information on societal norms, policies and current debate about healthcare and women's rights in various Hispanic countries and the United States. At the same time, it emphasizes the disabled female as subject, and investigates the societal perpetuation of disability. This dissertation discusses various concepts from disability studies, such as the illness/disability narrative, corporeal invisibility, normalcy, medical pathologization, stereotyping, and ableism, and investigates them in relation to both chronic and terminal illness or physical and mental disability in relation to the ill or disabled Hispanic female.

DEDICATION

I dedicate this dissertation to all the women out there who are living with illness, impairment, or disability. May you keep your heads high and your spirits higher.

To my fellow Type 1 diabetic friends, keep fighting.

ACKNOWLEDGMENTS

It is with extreme gratitude that I would like to thank my dissertation committee for their support and dedication to my academic success. To my dissertation chair, Dr. Carmen Urioste, I give infinite thanks for your continuous support in this process and encouragement to enrich my dissertation from an interdisciplinary perspective. Thank you for showing your understanding of my chronic illness and for being an inspiration by sharing your own struggle. To Dr. Cynthia Tompkins, I would like to express my appreciation for your patience and dedication to help grow my knowledge in feminist theory and literary analysis, pushing me to always be a better writer. I also express my gratitude to Dr. David William Foster. Thank you for introducing me to disability theory and for sharing your vast knowledge in regards to the former. It has been a pleasure working with all three of my committee members, and I thank each for their time and commitment throughout this process.

I would also like to thank my family for their continuous support and love, and for always believing in me and my dreams. Without you all, this would not have been possible.

In addition, I thank all my friends and church family for your optimism and patience as I went through this journey.

TABLE OF CONTENTS

CHAPTER 1

INTRODUCTION

The term *disability* is not a notion that is unknown to current society, its ubiquitous presence in law, healthcare and cultural products forms part of a societal discourse that affects the lives of hundreds of millions of citizens worldwide. According to Charles F. Szymanski in his article “The Globalization of Disability Rights Law from the Americans with Disabilities Act to the UN Convention on the Rights of Persons with Disabilities”, the universal nature of the term disability is a great source of discourse on disability rights in the global society, with an estimated 650 million people worldwide with disabilities. Syzmanski affirms that, “The existence of a disability cuts across issues of race, gender and even class and level of education. Tomorrow, anyone may be the victim of an unforeseen accident that leaves them permanently disabled” (22). This striking affirmation serves to show the connection between disability and the entire world population, affecting all of us at any given moment in time. However, typical western culture has been plagued by definitions of the (dis)abled based on stereotypes and pathological classifications, and almost always disregards the social experience and subjectivity of the impaired person. In fact, due to social constructions, illness, accidents, and old age, the disability identity is fluid, and may change based on each person’s individual experiences.

The work of disability theorists such as Lennard Davis, Simi Linton, Rosemarie Garland-Thomson, Michael Bérubé, and Nirmala Erevelles, amongst many others, has helped mold several distinct models of disability, placing emphasis on the social construction of disability and rejecting the medical model, a perception that focused on the curation of the impairment. These various theorists, at the same time, stress the importance of interdisciplinary connections, such as intersections of race, gender, and sexual orientation. By studying the various intersectionalities of disability, new and distinct perspectives emerge that are unique to the affected individual; while specific groups may have some things in common, each person has a different subjective experience.

Disability Studies in Spain and Latin America

In a recent article titled "¿Cuántas personas con discapacidad hay en España?", Europa Press stated that there are approximately 3.84 million people in Spain that are living with a disability, a number that makes up about 8.5 % of the entire population (n.p). According to this article, "Entre los problemas más frecuentes que causan la discapacidad —entendiendo por deficiencia cualquier problema en alguna estructura o función corporal— se encontraban las que afectaban a los huesos y articulaciones (39,3%), las del oído (23,8%), las visuales (21%) y las mentales (19%)" ("Cuántas" n.p.). Furthermore, amongst the 3.84 million disabled population, 2.3 million are women, more than half of the disabled population.

Equally important is the definition of the term disability in Spanish culture. According to the Real Academia Española, a disabled person, "padece una disminución física, sensorial o psíquica que la incapacita total o parcialmente para el trabajo o para otras tareas ordinarias de la vida" (RAE). This definition aligns with the social service codes created in 1991 by the once called Instituto Nacional de Servicios Sociales (now Inserso). These Códigos de Deficiencia, Diagnóstico, y Etiología outline various pathological situations of disability, from visual and auditory to intellectual and mental

("Base estatal" n.p.). While it seems that Spain does indeed recognize the varying types and degrees of disability, Benjamin Fraser asserts in his book titled *Disability Studies and Spanish Culture: Films, Novels, the Comic and the Public Exhibition* (2013) that, to date, there has yet to be published a book that focuses on disability issues in Spanish cultural productions or in Spanish society (xiv). Fraser explains, "Disability in Spanish cultural production —just as in Latin American cultural production— continues to be an almost completely unexplored area of academic research. Even works published in Spain on disability and culture tend to avoid a serious and sustained discussion of Spanish cultural products" (xv). However, as Fraser clarifies, the Anglophone models and notions of disability studies are relevant and applicable to Spanish society and its cultural products (xvi), forming part of a necessary social discourse on disability in Spain.

Similarly, in Latin America, the definition of the Americans with Disabilities Act and its human rights regulations for disabled people have a great deal of influence on the regional norms of Latin American countries. (Szymanski 26). The ADA defines a person as disabled if he or she has:

> (1) a physical or mental impairment that substantially limits the person in one or more major life activities, or (2) has a record of such impairment, or (3) is regarded as having such an impairment. Under the first prong of this definition, the ADA excludes environmental, cultural, and economic disadvantages, homosexuality and bisexuality, pregnancy, physical characteristics, common personality traits, normal deviations in height, weight, or strength, and the current use of illegal drugs. Even with these exclusions, the definition of the term disability is quite broad under the ADA. (Szymanski 25)

Implemented in 2001, the Inter-American Convention for the Elimination of all Forms of Discrimination against Persons with Disabilities ("Inter-American Convention" n.p.) was highly influenced by the ADA, as can be seen in their own definition of a disability: "a physical, mental, or sensory impairment, whether permanent or temporary, that limits the capacity to perform one or more essential activities of daily life, and which can be caused or aggravated by the economic and social environment" ("Inter-American Convention" n.p.). This definition combines medical and social elements that place emphasis on the social obstacles that limit the participation of disabled people in various spheres of social life ("Inter-American Convention" n.p.).

The definition of the Inter-American Convention is quite analogous to the main purpose of disability studies, which rejects the medical model and focuses on social problems associated with identifying oneself as disabled. Despite its title, disability studies is not necessarily limited to a distinct definition, rather it analyzes the disabled person as a subject, and discusses how the associated stereotypes with said identity are manifested and perpetuated due to societal norms. While there are a myriad of different disabilities that are legally recognized in both Spain and Latin America, this can oftentimes vary. However, legal recognition does not define if a person identifies themselves as disabled or not. Therefore, disability studies can be applied to any disability, illness, or impairment that impedes the daily life of the person, it is a theoretical framework and not a set of laws. In effect, oftentimes people that have a legally recognized disability do not wish to identify themselves as such. Consequently, the opposite situation may also occur, in which a person with an impairment or illness not recognized by disability law could identify themselves as a disabled person. Consequently, disability identity is fluid and is constantly changing.

According to Marja Mogk in her book titled *Different Bodies, Essays on Disability in Film and Television* (2013):

> Schematically, think of impairment as a physiological feature of a body, such as vision loss or paralysis. Think of disability on the other hand as a dynamic resulting from one or more features of an environment; social, cultural, political, historical, material or physical; that act as barriers or create exclusion, such as inaccessible stairs, poor lighting or prejudice. Thus disability is not a characteristic of an individual, but of a social reality. (4)

Therefore, an impairment is a physical characteristic and is only transformed into a disability when society creates barriers and perpetuates stigmas and stereotypes related with said impairment. Following the same line, in his article, "Disability, Pain, and the Politics of Minority Identity", Tobin Siebers explains it in this manner: "Disability identity is not based on impairment similarity but on social experience that includes a shared encounter with oppression, discrimination, and medicalization, on the negative side, and a shared knowledge of survival strategies, healthcare policy, and environmental conditions, on the positive side" (25). Furthermore, in her essay, "Reassigning Meaning", Simi Linton declares that:

> The question of who "qualifies" as disabled is as answerable or as confounding as questions about any identity status. One simple response might be that you are disabled if you say you are. Although that declaration won't satisfy a worker's compensation board, it has a certain credibility with the disabled community. The

> degree and significance of an individual’s impairment is often less of an issue than the degree to which someone identifies as disabled. (225)

Hence, the term disabled has a very fluid definition that can change from one culture to the next, depending of the societal and cultural norms of each group. In order to explain this notion, in his article, “(Post)colonizing Disability”, Mark Sherry states that:

> One of the best illustrations of the need for a culturally-specific examination of disability and impairment is O’Nell’s (1996) study of depression in a Native American community. Some Flathead Indian people suggested to O’Nell that between 70% and 80% of their community experienced depression. However, the incidence of depression was not generally connected to accounts of illness. Instead, a sense of suffering was regarded as a marker of maturity and Indian identity. For many people on the Flathead Reservation, depression is the natural and esteemed condition of ‘real Indians’, those who have used their sadness as a source of compassionate responsibility for others. (102)

In isolation, the depressive tendency of the Flathead Indians can seem like an ailment or a mental impairment that affects this already marginalized group due to previous colonialization. However, upon investigating their culture, the “depression” of this group is part of their identity and is not seen as an impairment. For that reason, it is vital to carry out the same investigations upon applying disability studies to Hispanic countries, because each one is going to have a unique set of cultural and societal norms.

Impairment, Illness and Disability in Literature

More than a legal term, disabled is an identity with which the person with the impairment decides to identify or not. Disability studies places focus on the individual lived experiences of the person with said impairment, and is more concerned with social constructions than medical fixes. Current disability studies is beyond the notion of a cure, it is giving a voice to those affected. Only recently has disability studies as a theoretical framework started to increase as an academic dialogue, although in relationship to literature proves to be somewhat scarce.

However, when used as a theme in literature, normally the disability is demonstrated only as a secondary theme, and does not emphasize the lived experience or subjectivity of the protagonist with the impairment. In his article, “Constructing Normalcy,” Lennard Davis explains that before, “If disability appears in a novel, it is rarely centrally represented. It is unusual for the main character to be a person with disabilities, although minor characters, like Tiny Tim, can be deformed in ways that arouse pity” (13). Thus, disability is transformed into a spectacle that ignores the subjectivity of the protagonist and perpetuates the stereotypes and stigmas that are associated with a disabled person. Nevertheless, Davis states that analyzing literature from a disability studies point of view, “can alter the way we see not just novels that have main characters who are disabled but any novel” (14).

As a society, applying this theoretical framework could create an understanding about the true experiences of the people that are normally seen as the Other in literature, by questioning the notion of normativity. Davis indicates that, “normativity in narrative will by definition create the abnormal, the Other, the disabled, the native, the colonized subject and so on," indicating that this is the nature of narrative (13). At the same time, in their essay, "Narrative Prosthesis," David Mitchell y Sharon Snyder affirm that a reader tends to "…forward readings of disability as a narrative device upon which the literary writer of "open-ended" narratives depends for his or her disruptive punch" (276). For the reader, this *performance* of disability in the narrative serves as an interrupting force that confronts cultural truisms (Mitchell and Snyder 275).

In terms of applying disability theory to Hispanic texts, the lawful categorization of the mentioned illness or disability in that society is not as important. For example, diabetes is not legally seen as a disability under Argentine law, but one would still be able to apply disability theory to an Argentine narrative in which diabetes is shown. The most important aspect is the exploration of the identity of the subject with the impairment and using disability studies theory to examine how said impairment affects the life of that person in society. Equally important to recognize is that it is necessary to investigate the culture, politics, history, and societal norms of whichever Hispanic country that is being studied when addressing the theme of disability studies in Hispanic literature. For example, colonialism has affected all Latin American countries, and consequently postcolonial studies are essential in the analysis of the literature of said countries. According to Sherry, "Disability and postcolonialism are two important, and inter-related, discourses in the social construction of the nation and of those bodies deemed worthy of citizenship rights" (94). Further along he confirms that, "An equally problematic response to the issues of post colonialism and disability is to marginalize the issues as if they were of concern only to those people who identify both as disabled and members of a colonized group" (100). Therefore, especially in Latin American Studies, many citizens may feel doubly colonized, not only due to the colonialization of their people, but also for identifying themselves as a person with a disability.

Feminist Disability Studies

As previously mentioned, there are a multitude of different intersections within disability studies, one of them being between gender and disability. With this relatively new awareness of the intersectionality in disability theory, the emergence of feminist disability studies as a theoretical framework has taken flight, with frontrunners such as Garland-Thomson, Abby Wilkerson, and Susan Wendell who delve into the subjective experience of the disabled woman. Due to the extreme relevance of feminist disability theory in today's society, analyzing cultural products using this new framework will help to open a dialogue on the intersectionality of the impaired or disabled woman. Therefore, examining contemporary literature based on this theory can provide insight to the present-day portrayal of impairment and disability in women and their experiences in society. Nevertheless, despite the growing popularity of feminist disability studies in the United States, using it to analyze narratives is few and far between, even though it forms a vital connection between literature and societal norms, such as the societal treatment of the term disability and the perpetuation of stereotypes and stigmas of the impaired or disabled woman. However scarce the application of feminist disability studies in contemporary literature in the United States, its use in contemporary Hispanic narratives appears to be almost non-existent.

Feminist disability studies is a relatively novel theoretical framework that began in the United States as a result of the need to analyze the lived subjective experience of women who suffer from an impairment or disability. The majority of this theory principally comes from Western first world countries whose resources differ greatly from those countries who are less developed. Various theorists recognize this difference, and aspire to produce more criticism from the point of view of these less developed countries whose culture and societies are unique to each of them, such as the case in Latin America. In fact, in his book *Disability and Poverty in the Global South: Renegotiating Development in Guatemala*, Shaun Grech states that:

> Much of disability studies is imbued with global North ideological, theoretical, cultural and historical assumptions, stripped of any engagement with global histories, transnational economics and politics (including development policies and practice), issues of race and geopolitical concerns, including poverty, its causes and manifestations and Southern resistance. This does not make disability studies theory or concepts irrelevant or unusable in the global South. (11)

Therefore, even though feminist disability studies originates from the United States, its theory can be applied to all countries in Latin America. At the same time, although Spain does not fit into the global south, the ubiquity of disability and its great population of disabled women warrant the application and study of feminist disability theory to Spanish society. That being said, while applying feminist disability theory, it is necessary to investigate the cultural, social, political and economic differences of each Hispanic region.

Although disability studies can be used to analyze contemporary literature by, and about, all gender identities, the proposed objective of this dissertation is a study and investigation of current disability theory and feminist disability theory, that will then be applied to narratives by female Latin American and Spanish contemporary authors. My study will investigate both Latin American and Spanish female authors who are chronically or terminally ill, impaired, or disabled. According to Susannah Mintz in her article, "Invisible Disability: Georgina Kleege's Sight Unseen":

> For a woman with some form of disability, the act of writing herself into a textual identity entails combating a triple erasure —from the long history of autobiography in the West, which has typically excluded women's experience from the kinds of life stories deemed worthy of recording, as well as from able-bodied culture and feminist theory, in which dis-ability has tended to be stigmatized as a sign of failure and inadequacy, or ignored altogether as a meaningful component of identity. It is from a position of cultural invisibility, then, that the female writer of disability narrative struggles toward a "performative utterance" that will announce the authority of her multiple unspeakable self. (69)

These "performance utterances" help to propel the female voice in current society, and place emphasis on the subjectivity of the ill, impaired or disabled woman. Consequently, I will examine how these authors' illness, impairment, or disability impacts the theme of their narratives, and will study the portrayal of this theme discussed in selected texts, almost all completely autobiographical. Even though this study will include commentary about a variety of different narratives, the main texts that will be studied are the following: *Fruta podrida* (2007) and *Sangre en el ojo* (2012) by Lina Meruane, *Diario del dolor* (2004) by María Luisa Puga, *Clavícula: (mi clavícula y otros inmensos desajustes)* by Marta Sanz, *Diario de una pasajera* by Ágata Gligo (1997), *Si crees en* *mí, te sorprenderé* (2014) by Ana Vives, and *The Ladies Gallery: A Memoir of Family Secrets* by Irene Vilar.

Although there are other Hispanic narratives by female authors that portray examples of illness, impairment and disability, this list of texts represents a great variation of societal perspectives in both Latin American and Spanish cultures, and embodies the relevance of textual analysis using this relatively new theoretical framework. Therefore, this study will serve as a discourse on current feminist disability theory in relation to contemporary Hispanic narratives and will show that despite originating in the United States, this theory can be adapted to any society as long as one keeps in mind the cultural, social, political and economic variations of each region being studied.

This text will be divided into three chapters, and each one will investigate how the authors' own life experience in relation to illness, impairment and disability serves as a theme for their narratives. In each chapter I will demonstrate how disability theory and feminist disability theory can illuminate how cultural norms create and perpetuate stereotypes in relationship to illness, impairment, or disability, and will dialogue about the fluidity of disablement as an identity. At the same time, this study will show how the application of feminist disability theory in contemporary literature by Hispanic women authors can open a cross-cultural discourse on the subjectivity of the ill or disabled woman and investigate the social and cultural construction of disability in Spain and Latin America.

Review of already completed research on this theme

Although there are various studies on the theme of pain in Hispanic literature by women authors, currently the application of disability studies and feminist disability studies to Hispanic narrative is few and far between. Two authors that I was able to find who investigate and analyze Latin American literature using disability theory are Beth Jörgensen and Susan Antebi. Jörgensen's research explores "the representations of disability in Mexican literature and culture" by looking at "fiction written by authors who do not claim a disability identity, and at diverse forms of writing (life-writing, blogging, poetry, fiction) created by or in collaboration with persons with disabilities" (Jörgensen n.p.). Jörgensen edited the following volume, *Libre Acceso: Latin American Literature and Film through Disability Studies* (2016). In comparison, Susan Antebi's "current research focuses on disability and corporeality in the contexts of Mexican cultural production" (Antebi n.p.). She is the author of the book, *Carnal Inscriptions: Spanish American Narratives of Corporeal Difference and Disability,* and co-edited the volume *Libre Acceso: Latin American Literature and Film through Disability Studies* with Jörgensen. However specialized, these authors focus on varied gender identities in strictly Latin America, while my investigation specializes in the disabled woman and includes Spain as well. On the other hand, when it comes to the analysis of disability in cultural productions of Spain, Benjamin Fraser has a volume that looks at some Spanish cultural productions, such as novels, films, and documentaries. This book, titled, *Disability Studies and Spanish Culture: Films, Novels, the Comic and the Public Exhibition* is a work that seeks to analyze "representations of disability in recent Spanish cultural products" (Fraser x) from a disability studies point of view. Much like Antebi and

Jörgensen's volume, this work focuses on all work from all gender identities only from Spain and does not use work made by authors/directors with a disability.

Chapter Summaries

In Chapter 1, titled, "Chronic Illness and (Dis)ability? The Social and Cultural Question of Type 1 Diabetes and (Dis)ability in Lina Meruane's *Fruta Podrida* and *Sangre en el ojo*" the reader see the effects of Type 1 diabetes as a chronic illness. In the realm of social and cultural perceptions of disabilities, unfortunately, many times chronic illness is not taken into consideration, most times due to its corporeal invisibility. Even though an individual with a chronic illness may or may not identify him or herself as disabled, it is important to keep this possibility in mind. That being said, using disability theory to analyze the connection between chronic illness and social identity is extremely beneficial to understanding the lives of many. Such a connection can be seen in cultural productions that, in many ways, exemplify the social stratospheres of their society, such as literary narrative constructions. Although chronic illness has been a leitmotiv in Hispanic literature throughout the centuries, there is little investigation when it comes to its connection with disability theory. In this chapter in particular, Type I diabetes appears in both of the novels, *Fruta podrida* and *Sangre en el ojo* by Lina Meruane, a Chilean author who suffers from the illness. It is clear that the personal affliction that Meruane faces has had an immense influence on the narratives she writes. These two contemporary works show the devastation caused by this illness, and in return the social perception of diabetes in both the Chilean and North American societies. In order to delve into the texts from a different, and much needed point of view, disability theory and feminist disability theory will be applied.

Investigating these texts from a feminist disability theory standpoint may seem problematic, and to some impossible. Unlike in the North American culture, many Hispanic countries do not see diabetes as a disability, it is simply an illness from which the person suffers. However, as was previously mentioned, feminist disability theory is not a political definition, it is a theoretical framework used to analyze and explore how this impairment/ illness affects the life daily life of said person. In the novels *Fruta podrida* and *Sangre en el ojo* by Meruane, the reader is able to notice the self-identification process of the diabetic protagonists, the stereotypes and social difficulties that go along with said illness, and the medical pathologization of both of the female protagonists. In *Sangre*, I will utilize *Sight Unseen* by Georgina Kleege, highlighting the difference between being born blind and developing this disability later on in life. In *Fruta*, I will discuss the medical gaze, and the rejection of the pathological notion that all disabled persons want to be cured. Analyzing these works in a social and cultural context using this type of theory will provide a deeper look at those afflicted, and how cultural misconceptions of the term disabled are reproduced, especially in terms of chronic illness.

The second chapter, "Feminine Corporeal Deterioration and Literary Catharsis in *Diario del dolor* by María Luisa Puga, *Clavícula* by Marta Sanz and *Diario de una pasajera* by Ágata Gligo" studies the hysteria of women in relation to medical diagnoses and the warped experiences that they have with the medical professionals that treat them. Once known as the fairer of the sexes, women oftentimes are denominated as crazy, fragile, helpless, weak, vulnerable, dependent and incapable bodies (Garland-Thomson 19). This portrayal has been wrongfully associated with women throughout history, cohesive to the political and societal norms of the patriarch. Consequently, this is why feminist disability studies are so vital to exploring the social and medical construction assigned to disabled women. In her essay “Integrating Disability, Transforming Feminist Theory”, Garland-Thomson states that:

> Feminist disability theory offers a particularly trenchant analysis of how the female body has been medicalized in modernity. As I have already suggested, both women and the disabled have been imagined as medically abnormal —as the quintessential sick ones. Sickness is gendered feminine. This gendering of illness has entailed distinct consequences in everything from epidemiology and diagnosis to prophylaxis and therapeutics. (22)

In *Clavícula, Diario del dolor*, and *Diario de una pasajera,* the reader observes the autobiographical narratives of these three authors, Gligo with breast cancer, Sanz with an unknown illness, and Puga with rheumatoid arthritis. In each narrative, they provide the reader with a realistic account of their experience with pain and illness, and their realization of their decaying, menopausal bodies. At the same time, they expose how they use writing as a cathartic tool, something I will examine in detail using narratology theory.

Furthermore, in Chapter 2 I will talk about the gendering of illness, corporeal deterioration over the longue durée, and literary catharsis in conjunction with illness. In order to discuss the consequences of gendering illness feminine, I will analyze each text using feminist disability theory and corporeal theory by Judith Butler and Michel Foucault, and will draw upon Elaine Showalter’s *The Female Malady* to discuss stereotypical generalizations about the female body.

Finally, Chapter 3 of this dissertation focuses on the disabled mind, delving into both genetic disorders and mental illness. In this chapter, titled, "Genetic Disorders and Mental Illness: Living With Down Syndrome in *Si crees en mí, te sorprenderé* by Anna Vives and Mental Illness in Irene Vilar's *The Ladies Gallery: A Memory of Family Secrets"*, we see a juxtaposed comparison of mental illness and cognitive impairment, two very different forms of disability. While the definition of cognitive and physical ableism varies from one society to the next, when a person appears unlike the rest of the able-bodied community, prejudicial and stereotypical images are formed. In *Si crees en mí, te sorprenderé* Anna Vives is a young girl with Down Syndrome and although she is cognizant of her disability, strives to break with typical stereotyping associated with her genetic disorder. In her autobiographical narrative, a genre Fraser affirms is increasing in the Spanish society (xv), Vives, who works with author Francesc Miralles to create a collaborative autobiography, exposes her experience with a (dis)ability in an ableist society, many times touching on inclusion, assimilation, and difficulties she faces. In their article "Handicapism", Douglas Biklen and Robert Bogdan affirm that many times people with disabilities follow their stereotypes and are rewarded for living up to them (5), causing a negative effect and highlighting their disability. Nevertheless, in *Si crees,* Vives' support systems encourage her to focus on her capabilities and not her disabilities. When analyzing this text, it will be necessary to analyze the positives and negatives about writing collaborative autobiographies, touching on the integrity of the text. At the same time, this chapter utilizes various notions from disability theory such as normalcy, able-bodiedness, and the fluidity of disability identity. This section of the third chapter will focus on the social and cultural construction of normalcy, and the subjective experience of a female living with a cognitive disability.

Although mental illness is a prevalent disease that affects millions of people worldwide, there seems to be unnecessary stigma attached to the suffering from one. Therefore, the second part of Chapter 3 of my dissertation will analyze mental illness in the Hispanic narrative *The Ladies Gallery: A Memoir of Family Secrets* (2009) by the Puerto Rican author Irene Vilar. Unfortunately, mental illness has been associated with hysteria, generally assigned to women. In this chapter, I will incorporate Sandra Gilbert and Susan Gubar's book *Madwoman in the Attic* (1978), and Elaine Showalter's *The Female Malady* (1985) in order to analyze the gendered history of madness. While mental illness has appeared in literature throughout the centuries, current autobiographical work can help transform the way in which it is seen. In her autobiographical narrative *The Ladies,* Vilar opens up about her familial history of suicide and psychiatric illness, as well as sharing her own experiences at a mental institution. By examining her memoir using feminist disability theory, I will analyze *The Ladies* by emphasizing the pathologization of mental illness, the societal stereotypes that are normally attributed to it, and the negative treatment they receive by the professionals who handle their cases. At the same time, I investigate the attribution of mental illness to rebellious women, a way of mitigating their nonconformist behavior, and thus taking away from those who truly suffer from a psychiatric disease.

CHAPTER 2

CHRONIC ILLNESS AND (DIS)ABILITY? THE SOCIAL AND CULTURAL QUESTION OF TYPE 1 DIABETES AND (DIS)ABILITY IN LINA MERUANE'S *FRUITA PODRIDA* AND *SANGRE EN EL OJO*

Living with a chronic illness can be a challenging and debilitating daily struggle that many times goes unrecognized due to its invisibility to those around. At the same time, chronic illness can foster an identity fluctuation between the able-bodied and disabled, and reminds the person inflicted that, "the body is, as Denise Riley asserts, 'an unsteady mark, scarred in its long decay'" (Garland-Thomson, "Feminist" 33). According to disability theory, a person living with a chronic illness is reminded of this "long decay" every day, and many times faces a world in which one's invisible illness is stigmatized by the medical need for a cure and the stereotypes associated with the illness. In Lina Meruane's *Sangre en el ojo* (2017) and *Fruta podrida* (2016), the female protagonist has Type 1 diabetes, an illness that, in particular, is extremely stigmatized in today's society: a substantial amount of people believe that Type 1 diabetics are responsible for getting the disease and in fact blame that person for their malady (Vishwanath 524).

However, in today's culture, many women living with a chronic illness are rejecting the medical model of disability theory that focuses on the need for a cure and are opening up about their lived experiences by using life-writing. In feminist disability studies, this life-writing is what Rosemarie Garland-Thomson denominates *situated theory*. In her article, "Feminist Disability Studies," Garland-Thomson states that "situated theory offers a feminist disability epistemology that protests the disability system" (1569). As an example, she explains how various women authors have written about their own disability by placing emphasis on their own subjectivity. While Garland-Thomson discusses American women writers who do this, I use the Chilean narratives *Sangre* and *Fruta* by Meruane that align with situated theory, as it stresses the subjectivity of the female protagonists who suffer from type 1 diabetes, a biographical aspect of Meruane. In their book *Reading Autobiography: A Guide for Interpreting Life Narratives*, Sidonie Smith and Julia Watson discuss how many authors who write about trauma, such as violence, illness, or disability, oftentimes have a hard time remembering exact details of the events and, therefore, resort to including fictive elements (27). This hybrid type of writing invites readers to both contemplate the veracity of the narrator's story and validate her/his claims (Smith and Watson 33). At the same time, readers must confront the fate of the ill or disabled body, whether it be the author's or their own (Smith and Watson 53).

In addition, Smith and Watson discuss the fact that autobiography has not been an easy task for postcolonial women writers. They cite Gayatri Spivak who argues that the genre of self-reflexivity is difficult for these female authors because of the genre's traditional ties with possessive masculinity (129). Smith and Watson continue by stating that the "detour" from autobiography to fiction makes the postcolonial woman writer less vulnerable to exoticization/shaming in their culture (129-30). However, the authors also state that, "In positioning themselves as disabled subjects who address the history of their own marginalization, disabled writers reframe their impairment by refusing the diagnosis of disability or stigmatized abnormality" (143). Perhaps Meruane's narrative, as the authors above stated, aims to avoid the vulnerability that she might possibly face as a postcolonial woman writer exposing her disabled body by including fictive elements, while at the same time rewriting the history of her stigmatized experience.

In her narratives, Meruane breaks the traditional representations of the ill or disabled person that "not only restrict the lives and govern the bodies of people we think of as disabled, but limit the imaginations of those who think of themselves as nondisabled. Stereotypical, often unexamined narratives ultimately undergird exclusionary environments, employment discrimination, and social marginalization" (Garland-Thomson, "Feminist" 1567). Although Meruane addresses her own illness in the novels *Sangre en el ojo* and *Fruta podrida,* placing subjectivity on the two main female protagonists, the reader observes the struggle that these women face in the plots not only to conform to able-bodied normalcy, but also as they are socially marginalized due to their chronic illness. Consequently, the following sections will examine type 1 diabetes in the books *Sangre* and *Fruta,* and this chapter will breakdown as the following: a brief description of the relevance of disability studies in Chile, an overview of the legality of diabetes as a disability in both Chile and the United States (countries in which the narratives take place), a brief synopsis of *Sangre* and *Fruta*, and an analysis of the narrative using the following disability theory notions: disability acquisition, disability identity, stereotyping and marginalization, and medical pathologization.

Disability Studies and Diabetes in the United States and Chile

According to Nirmala Erevelles in her article "The Color of Violence: Reflecting on Gender, Race, and Disability in Wartime," "In contexts where subsistence is a struggle, third world disabled people in general, and third world women who are themselves disabled and/or caregivers for disabled family members/clients, face the social, political, and economic consequences of invisibility" (117). She then goes on to state that "it is critical that third world feminists and feminist disability theorists examine the impact of disability on (both nondisabled and disabled) third world women's lives as they struggle against the oppressive policies and practices of the imperialist/neocolonial state" (128). Therefore, applying disability theory to the analysis of literary products that exemplify the lives of disabled women in Chile is extremely relevant. When it comes to *Sangre* and *Fruta*, utilizing disability theory is particularly pertinent to dissect and examine the lived-experience of the protagonists, because the most vital aspect of the analysis is the exploration of their subjectivity and how their disability identity is further propelled by society.

However, in their book *Libre Acceso: Latin American Literature and Film through Disability Studies,* Susan Antebi and Beth Jörgensen confirm that, to this date, disability studies in Latin America are found more in social sciences and not literary discourse (4). Furthermore, the authors also state that disability and Latin American studies have in common the objective of exploring body politics and engaging with minority groups, such as women (7).[1] Therefore, there is a necessity to expand disability studies and Latin American literary discourse. For this reason, in both *Fruta* and *Sangre*, utilizing disability theory is particularly pertinent to dissect and examine the lived-experience of the protagonists, because the most vital aspect of the analysis is the exploration of her subjectivity and how her disability identity is further propelled by society.

---

[1] According to Antebi and Jörgensen, disabled people have been named as the world's largest minority group (10), and that poor living conditions in the Global South only increase the disability phenomenon (13).

In order to provide an accurate analysis of type 1 diabetes as a theme in these two narratives, I investigated the pathological and political identification of diabetes in both Chilean and American culture, the two countries in which *Fruta* and *Sangre* take place. In the United States, diabetes is legally considered a disability, as outlined by the American Diabetes Association:

> Diabetes limits the endocrine system. This is the system that regulates insulin and blood glucose (sugar). Specifically, federal laws, such as the Americans with Disabilities Act and the Rehabilitation Act, protect qualified individuals with a disability. Since 2009, amendments and regulations for these laws make clear that diabetes is a disability since it substantially limits the function of the endocrine system. This internal limitation is enough—no outside limitation is necessary. This means diabetes can be an "invisible" disability. (ADA n.p.)

While this protection, however, can help prevent workplace discrimination, this does not deter societal stereotyping and stigmatization. According to Arun Vishwanath in his article, "Negative Public Perceptions for Juvenile Diabetics: Applying Attribution Theory to Understand the Public's Stigmatizing Views," "Most of the information about diabetes generally comes from its presentation in the mass media, where much of the focus is on Type 2 adult onset diabetes" (517). Consequently, the media tends to erroneously put Type 1 into the same category as Type 2, which is caused by "genetics, lifestyle, and poor eating habits" (517).

When it comes to Chilean society, diabetes is not considered a disability. In their document titled *Discapacidad en Chile*, González et al. state that according to the CIF

(Clasificación Internacional del Funcionamiento, de la Discapacidad y de la Salud), the requirement for an illness or impairment to transform into a legal disability is "toda alteración o atributo del estado de salud de un individuo que puede generar dolor, sufrimiento o interferencia con las actividades diarias, o que puede llevar a contactar con servicios de salud o con servicios comunitarios/sociales de ayuda" (12). This document, gives the example of a diabetic child, and how said situation has the possibility of changing into a disability:

> Un niño diabético: deficiencia en el funcionamiento del páncreas para producir insulina, la cual, al estar controlada no produce limitaciones en la capacidad del niño para realizar sus actividades diarias y vitales. Sin embargo, a la hora de comer y compartir dulces con sus amigos pueden surgir problemas en el desempeño y/o realización de esa actividad producto de la carencia de alimentos apropiados para él, con la consecuente y posible restricción de sus niveles de participación en ese tipo de actividades (factores contextuales). (12)

Even though diabetes is not legally considered a disability in Chile, people with this illness can develop problems caused by said illness that are indeed categorized as a disability under Chilean law. These problems include, but are not limited to: diabetic retinopathy, blindness, hypoglycemia, diabetic ketoacidosis, coma, gastroparesis, and heart and kidney disease and failure. This fluctuation of disabling factors aligns with the notion from disability theory that identifying oneself as a disabled person has the possibility to change, it is a fluid identification. In his article "Lost and Found in Space," Brendan Gleeson explains that the majority of people in any community are going to suffer from an impairment at some point in their life, which could lead to identifying as disabled (69). Therefore, identifying as disabled can change day-by-day.

Furthermore, according to a study of Argentina, Brasil, Chile, Colombia, Ecuador, El Salvador, Guatemala, Honduras, Nicaragua, Paraguay, Perú, República Dominicana, Uruguay, "las enfermedades crónicas son consideradas como la principal causa de la discapacidad en 63,6% de los países" (Álvarez-Martín y Neves-Silva 4892), and this inlcudes diabetes. According to a Chilean government document titled, "El reto de la diabetes en Chile," "la diabetes es la principal causa de muchas complicaciones debilitantes y costosas, incluyendo la enfermedad de riñón, que en última instancia puede provocar insuficiencia renal. Chile tiene la segunda tasa más alta de terapia de reemplazo renal en América Latina con un número de casos que aumentó en más del 40% entre 2001 y 2010" (3). Consequently, one can easily see that there is a diabetes and its subsequent consequences in Chilean society, so the application of said theme in literature is highly relevant.[2]

Fruta podrida and *Sangre en el ojo:* A Brief Synopsis

As previously mentioned, in both of the narratives the main protagonists suffer from type 1 diabetes: Zoila in *Fruta*, and Lina in *Sangre*. In each book, both Zoila and Lina are presented as having grown up with the illness from a young age. Due to the damaging effects that type 1 diabetes can cause the people who suffer from it, both protagonists face challenges that inhibit daily tasks and performances.

---

[2] As of 2017, 8.5% of Chile's population between the ages of 20-79 have diabetes. In comparison, Colombia is at 7.4%, Honduras 7.2%, Nicaragua 11.5 %, Venezuela 6.5%, Ecuador 5.5%, Uruguay 6.9%, and Paraguay at 8.4% ("Diabetes Prevalence" n.p.).

During the plot of *Sangre*, the main protagonist Lina is presented as having grown up with the illness from a young age. Due to the damaging effects that type 1 diabetes can cause the people who suffer from it, the protagonist faces challenges that inhibit daily tasks and performances. As aforementioned, *Sangre* is a text that appears to be what Smith and Watson denominate as "autofiction" (10), incorporating the life-story of Meruane, a type 1 diabetic, while blurring the boundary between fact and fiction. According to Smith and Watson, novels and life-writing share common features such as plot, settings, characterization, dialogue (10). However, they add, the two are:

> Distinguished by their relationship to and claims about a referential world. We might helpfully think of what fiction represents as "a world," and what life writing refers to as "the world." Further complicating matters, many contemporary writers deliberately blur the boundary between life writing and the kinds of stories told in the first- person novel that some call "fiction," others "autofiction." (Smith and Watson 10)

This is exactly what occurs throughout the narrative of Meruane. While taking real-life events from her past, she develops a story that, while exposing her battle with illness and disability, also incorporates fictive liberty to narrate these events.[3] During the plot, Lina, becomes partially blind after complications from diabetic retinopathy, an illness in which the blood vessels of the eye become damaged due to high blood sugar levels. In fact, Meruane states in her essay, "Blind Spot," that the writing of *Sangre* was provoked by her own experience of temporary blindness (30). After discovering that her sight will

---

[3] Antebi and Jörgensen similary affirm that *Sangre en el ojo* "represents a literary transformation of the writer's own experience" (13).

probably not recover, Lina, who is currently studying her graduate degree in New York City, takes a trip to Chile to visit her family. Along the way, she discovers the difficulties of living with a disability and experiences stereotyping by both strangers and family. After she returns to the United States, Lina becomes desperate for a new pair of eyes and decides that she wants a transplant, asking her boyfriend, Ignacio, for his.

The narrative commences by explaining the onset of Lina's diabetic retinopathy. Although the focus of the plot is indeed the chronic illness and disability of the protagonist, Meruane mixes her lived-experiences with diabetes along with fictional narration, something that the author believes gave her more liberty in her self-expression. [4] This emphasis on self-expression is extremely vital to feminist disability studies as it places importance on the lived experience of the disabled woman. From the very beginning, the reader is able to see the subjectivity of Lina as she explains the onset of her blindness: "Estaba sucediendo. En ese momento. Hacía mucho me lo habían advertido y sin embargo. Quedé paralizada" (*Sangre* 11). Later on she states:

> Yo acababa de entrar en la pieza matrimonial, acababa de inclinarme, yo, en busca de mi cartera y la jeringa. Tenía que pincharme a las doce en punto pero no alcanzaría a hacerlo…Y fue entonces que un fuego artificial atravesó mi cabeza. Pero no era fuego lo que veía sino sangre derramándose dentro de mi ojo. La sangre más estremecedoramente bella he visto nunca. La más inaudita. La más espantosa. (*Sangre* 12)

---

[4] In an interview, Meruane states that *Sangre* mixes autobiographical events with fiction because it permitted her to draw upon events her memory might not remember one-hundred percent. She states: "Yo, que siempre he estado más cómoda en la ficción, porque la ficción ofrece libertades que la memoria parece no permitirnos, me pregunté qué hacer, es decir, cómo narrar un episodio dramático que mi pasado me ofrecía" ("Lina" n.p.).

According to Elena Álvarez-Martín and Priscila Neves-Silva in their article, "Estudio descriptivo de las características sociodemográficas de la discapacidad en América Latina", "La hipertensión arterial, la diabetes y el ictus son enfermedades que muchas veces promueven discapacidad como la ceguera y las discapacidades motoras, que son los tipos de discapacidades más prevalentes en América Latina según este estudio y que coincide con otros" (4895). In the novel, blindness had begun to affect Lina, and as demonstrated in the quote by Álvarez-Martín and Neves-Silva, is a common disability caused by diabetes. Meruane successfuly exemplifies the negative consequences that this illness produces. By doing so, her life-writing opens up a discourse on the female embodiment of this illness.[5]

Throughout the plot of *Fruta,* which Meruane affirms is "governed by the degenerative logic of diabetes" ("Blind Spot 35), revolves around two female protagonists, María, the older sister, and Zoila, the younger diabetic sister. Throughout the novel, Meruane presents us with both sisters' points of view, Zoila a chronically ill woman who has no desire for a cure for her disease, and María, a fruit farm employee specializing in the prevention of parasites. After Zoila falls dangerously ill and is admitted to the hospital, the doctor explains to María that her sister has type 1 diabetes. However, while her sister and the team of doctors try to control the illness of Zoila, she refuses to become compliant and stifles the plan of María to cure her, who began selling fetuses to the hospital in order to save for a pancreas transplant for her younger sister. Once María realizes the unwillingness of her sister and the lack of recognition at her job,

---

[5] Meruane states that life-writing, by herself and author authors, forces the author to face their own story without the omission of the first person or their own name ("Blind Spot" 31).

she takes revenge by poisoning the fruit she is in charge of with cyanide. At this time, Zoila flees Chile to a northern metropolitan country (one can assume the United States as she previously mentioned big cities such as New York and Philadelphia), where she begins her attacks at a hospital by cutting off the life support of various young patients. The novel ends with a dialogue between her and one of the nurses from this hospital, who, when searching for Zoila's identification, discovers the gangrene and necrosis of Zoila's injured foot.

Similar to *Sangre*, when Zoila is introduced into the plot of *Fruta*, Meruane uses the first person, even though, at the very beginning of the novel, her older sister María talked about her only in the third person and never directly to her, equating her existence to a parasite. For example, in one of the opening scenes, María explains: "Observaba la escena, la contemplaba con la repentina frialdad de su ojo entomólogo: Zoila era un bicho recién fumigado. Era una mosca enredada en la alfombra de la araña, el puro armazón de un insecto recién vaciado" (*Fruta* 15). Later, after María finds out about the illness of her younger sister, she describes the medical diagnosis of the doctor:

> No se sabía suficiente sobre cómo proceder para evitar la aparición de esa enfermedad que resultaba tan sorprendente para la ciencia: como le decía, dijo el Médico, no es una enfermedad contagiosa pero sí transmisible, porque posiblemente, muy probablemente, es una condición latente, hereditaria, que de pronto se detona, estalla sin aviso, y a partir de ese momento el sistema defensivo empieza a recibir órdenes contradictorias, resoluciones suicidas. El propio cuerpo se rebela contra sí, el cuerpo hace de sí mismo su propio enemigo. (*Fruta* 25)

However, once the narration is taken over by Zoila, the reader notices that María begins to talk directly to her. It is in the first scene in which Zoila is transformed from an object into a subject that the reader gets a look into the life of a type 1 diabetic, much like Lina's subjectivity in *Sangre*. Zoila begins her narration by describing a hypoglycemic episode, aware of her body's malady. "Llega la noche y ya no hay cómo apaciguar este rumor: un fuego rabioso y ávido me corroe las tripas. Y me zafo silenciosa de las sábanas, y voy avanzando con urgencia a la cocina" (36). Almost immediately after, Zoila describes a near-death experience caused by her hyperglycemia:

> Un paso más y se me doblan las rodillas. La insulina que acabo de ponerme a escondidas de mi hermana, esa dosis que me permite robar dulces sin ser descubierta, ha empezado a hacer su efecto. Pero aquí, ahora, no hay con qué paliar este vertiginoso bajón de azúcar en la sangre que me va aturdiendo. Las hélices torcidas de mi cerebro empiezan a quedarse sin electricidad. Y tengo que pensar en algo pero ya no pienso…Se me nubla la vista, me palpita la cabeza. Chispazos eléctricos se encumbran por mi nuca, hacia el cráneo: estoy al borde de un cortocircuito…mis neuronas piden desesperadamente azúcar, azúcar, una y muchas veces azúcar repitiendo el sabor acaramelado de esa palabra hasta que lentamente todo se deshace en un sudor insulso…(*Fruta* 36-37)

For any reader, aware of the devastating effects of type 1 diabetes or not, this scene exemplifies the daily struggle that living with this illness produces. By doing so, this life-writing aligns with situated theory and can be seen as a tool to help battle stereotyping and inclusion and place emphasis on the embodiment of a disabled woman.

Disability Acquisition: A Life Changing Experience

Many times type 1 diabetes and its damaging side effects do not occur until later on in life. As previously mentioned, illness, in general, reminds us that the human body is forever changing, and that a person may one day wake up with a disability. According to feminist disability theorist Susan Wendell, this experience can be eye-opening. She explains her experience once she began fighting a chronic illness: "I had to learn to live with a body that felt entirely different to me—weak, tired, painful, nauseated, dizzy, unpredictable. I learned at first by listening to other people with chronic illness or disabilities; suddenly able-bodied people seem to me profoundly ignorant of everything I most needed to know" ("Toward 336). Wendell agrees that life-writing is essential to fully understand disabled women in society, as it "offers vital insights into the nature of embodiment and the experience of oppression" ("Toward" 337). The texts of Meruane does just that; it sheds light on the embodiment of chronic illness, and at the same time demonstrates the social marginalization and stereotyping that a disabled and chronically ill woman may face, a theme that will be discussed in greater detail further along.

Just like Wendell, during the plot of *Sangre* and *Fruta* alike, the diabetic protagonists must face life-changing effects caused by the onset of their illness and disability. In *Sangre*, Lina is forced to change her lifestyle because of the onset of her blindness. According to Javier Guerrero and Nathalie Bouzaglo in their book *Excesos del cuerpo: Ficciones de contagio y enfermedad en América Latina*, the plot of *Sangre* presents the disorganization of the life of Lina and her surroundings following the onset of her disability (48). The protagonist Lina expresses this disorganization and subsequent difficulties various times, the first being when she is traversing New York City, her place of study. Lina states that, "El recorrido conocido ya no coincidía con mis pasos. No distinguía árboles de semáforos en esa marea turbia, no podía asegurar que fueran autos lo que percibía junto al posible parque de la esquina. Avanzaba como un murciélago desorientado, siguiendo intuiciones" (*Sangre* 24). In another scene she begins to become frustrated by her new condition, and describes that, "cambiaba de forma, la casa, enrocaba las piezas, permutaba los muebles para confundirme. Con un ojo ciego de sangre y el otro empañado por el movimiento andaba más perdida, más gallina vendada, mareada y turuleca. Pero me secaba unas lágrimas hurañas y volvía a medir los pasos, a memorizar" (*Sangre* 29). At this point, she recognizes that she must try to become accustomed to this new disability. Much like Helen Keller's "The World I Live In" (1908) [6] and Georgina Kleege's *Sight Unseen* (1999), Meruane's account of the protagonist Lina places emphasis on the embodiment of blindness and her struggle to cope with the diagnosis. Susanna Mintz comments on the life-writing of Kleege, stating that, "Kleege's story foregrounds the conflictedness of female disabled subjectivity in a culture that privileges male able-bodied independence, the paradox of having to accept marginalized status along with the pressure to conform and perform "normally" (72). Similarly, Meruane's autobiographical narrative portrays this same "conflictedness" as Lina is forced to conform to a primarily sighted world.

Furthermore, along with her onset of blindness, the persistence of her chronic illness continues to cause various difficulties for Lina. In one scene, she had forgotten her insulin at home, and if not taken, the result can be deadly. For example, the excess of

---

[6] Helen Keller says, "The calamity of the blind is immense, irreparable. But it does not take away our share of the things that count—service, friendship, humor, imagination, wisdom" (288). Much like Kleege, Keller recognizes the struggle of being blind, but also the characteristics that tie them to the sighted.

sugar in the blood can cause ketoacidosis, a life-threatening condition that can lead to difficulty breathing, nausea and vomiting, diabetic coma, or death (ADA n.p.). Upon realizing her mistake, Lina explains how her blindness was the culprit: "Empezamos a morder un pedazo de marraqueta algo dura y un vino algo tibio, y en cuanto nos trajeron los platos me percaté del olvido. (Mi cartera. La jeringa con insulina. La olvidaba porque no podía verla…)" (*Sangre* 101). Although there are often cases in which blindness can be cured by corneal transplants, type 1 diabetes does not have a cure, and Lina recognizes this. In the narrative, Lina explains upon arriving to the hospital that:

> Ahí estaba archivado el registro de mis ojos. En la memoria subterránea del hospital yacían cientos de esplendidas imágenes de la ruina. Me senté en la recepción apretando los puños contra las sienes, sabiendo que iban a operarme pero que la curación no existía. La enfermedad iba a persistir por más que me abrieran y cerraran. (*Sangre* 129)

Due to the fact that Lina has suffered from type 1 diabetes for many years, she has come to accept its pervasiveness, unlike the sudden acquisition of her blindness, a theme that will be elaborated in the following sections.

In contrast to *Sangre*, in the plot of *Fruta* the diabetic protagonist does not go blind, although she begins to experience the onset of diabetic retinopathy caused by her chronic illness. In the last section of the novel, Zoila states, "No ves bien y sabes que pronto no verás casi nada" (*Fruta* 128). The life of young Zoila instantly changes after receiving the news of her type 1 diabetes, and the reader follows along with the deterioration of her body and daily struggles. In another instance, Zoila recognizes the limits of her decaying body, but, unlike Lina in *Sangre*, does not try to fight it. She explains: “Mi cuerpo es una fruta ya madurada: pese a la delgadez que provoca mi extrema dulzura, estoy aumentando bajo la ropa, me redondeo por todos lados. Está creciéndome pelo en lugares inesperados y de mí ahora surgen líquidos extraños” (*Fruta* 72). Although Zoila recognizes the deterioration of her body, she embraces the changes rather than trying to fix them. Instead of insisting on a cure, Zoila goes against the medical pathologization of doctors and rejects any efforts to control her illness.

In her essay, Meruane explains that Zoila’s decision demonstrates “the natural strength of imperfection, the expected horizon of the unhealthy, the organic cycle of life and death” (“Blind Spot” 36). In stark contrast to Lina’s opposition to illness and disability, Zoila fervently seeks the end of her life.[7] The reader observes the medical binary illness/cure, although it is not Zoila who wishes to minimize her suffering. Guerrero and Bouzaglo delineate that in self-representational literature, many times the author exemplifies illness as a style of life (27), and that oftentimes illness is used as a metaphor of greater proportion, such as to represent collective society (16). In *Fruta*, the resistance seen by Zoila, represents something even greater: the opposition to the “capitalist system of incessant production” (“Blind Spot 36). The fermentation of her contaminated body threatens the collective good and instills in the *healthy* a fear of transforming into the Other, something Guerrero and Bouzaglo indicate goes against social progress and well-being (23). An example of the metaphor of Zoila’s contamination occurs as she enters the foreign country on route to the great hospital. She states, “recuerdas toda esa fruta devuelta en los grandes contenedores, en la fruta detenida

---

[7] In “Blind Spot”, Meruane refers to Zoila’s opposition to the capitalist medical system as a death wish (36).

en los sucesivos camiones rojos de la empresa. Tú serás la fruta que pase inadvertida" (Meruane 123). This affirmation shows Zoila's representation as the contagion, the Other, as the threat to societal order.[8]

Disability Identity?

Throughout both narratives, the diabetic protagonists have very different self-identity experiences, displaying two types of disability orientation as outlined by Rosalyn Benjamin Darling: identity pride or shame (9). She affirms that some people with a disability "play the classic sick role and continue to search for cures for their impairments, whereas others may choose to forgo rehabilitative services" (10). On one hand, Zoila takes pride in her disability identity and completely rejects the notion of a cure. This cure-based ideology is aligned with popular culture that Garland-Thomson says, "permeates the entire cultural conversation about disability and illness" ("Integrating" 27). Popular culture discards what Wendell has denominated "the rejected body" and causes the tendency for disabled people to hesitate in self-identifying due to stigmatization and negative stereotyping.[9] This disability identity shame appears in *Sangre* after Lina acquires her blindness. In contrast to Zoila, who accepts her disabled state, Lina vehemently resents the loss of her sight and seems to have forgotten who she was before her blindness. In a way, her rejection and negative outlook of this new disability verifies what Karen Elizabeth Jung outlines in her article "Chronic Illness and Educational Equity: The Politics of Visibility" that, "living with the fundamental

---

[8] Meruane explains that in both *Fruta* and *Sangre*, she strived to "add pathology to the social imaginary of the normal" ("Blind Spot 37).

[9] The term "rejected body" by Wendell is found in her book *The Rejected Body Feminist Philosophical Reflections on Disability* (1997).

conditions of an ill body does not merely involve the experience of contingency, lack, and limitation in activity and role performance; it also inaugurates consignment to an identity category that signifies disadvantage and oppression (Garland-Thomson 1998): those who are disabled" (263).

After the loss of her sight, Lina's sense of identity wavers in a struggle to cope. In fact, Meruane states that the protagonist "oscila entre la ceguera permanente y la recuperación de la vista es un personaje movilizado por la ira, por el deseo iracundo de superar la crisis, y esa energía la lleva a valerse de todo el que se le ponga por delante. Esta mujer está dispuesta a todo, menos a ser la víctima de su cuerpo" ("Lina" n.p.). For example, Lina's identity confliction is apparent while in the office of her ophthalmologist after the receptionist calls her complete name, Lucina Meruane, At first she does not even recognize it: "¿Entonces eres o no Lina Meruane? A veces soy, dije, cuando los ojos me dejan; últimamente cada vez soy menos ella para volver a Lucina. La sílaba extra sangraba a veces" (*Sangre* 31).[10] Though a difficult notion to accept, Garland-Thomson expresses that "we are better off learning to individually and collectively accommodate bodily limits and evolutions than trying to eliminate or deny them" ("Integrating" 34). Similarly Mintz asserts that Georgina Kleege's *Sight Unseen* is about the author's own story of guilt, defiance, and self-creation, finding identity in her blindness on her own terms (Mintz 71). Perhaps *Sangre* is an outlet for Lina Meruane's self-expression and disabled identity acceptance, much like Kleege's life-writing narrative, something

---

[10] Meruane expreses that she had debated on whether to include her own name in the story, but that by doing so, she created an illusion for the reader: "that Lucina would sign her novel as Lina made her name a fiction" ("Blind Spot" 33).

Garland-Thomson believes to be essential in placing subjectivity on the disabled woman ("Feminist" 1569).

At the same time, throughout the plot of *Sangre* Lina recognizes that she will now have difficulty writing, one of the many aspects that once defined her. In her book, *Disability and Identity: Negotiating Self in a Changing Society* (2013), Darling states that, "identities are defined as internalized role expectations. These identities, in turn, are organized in a hierarchy of salience" (8). The role that Lina once played as a sighted writer has suddenly transformed, and the internalization of this role expectation which she now cannot fulfill has thrown off her identity equilibrium. At one point she reflects, "Y también los libros que yo había publicado bajo un nombre inventado y el manuscrito de una novela inconclusa que quizá ya no acabaría, pensé, tragándome la angustia sin detenerme a masticarla" (*Sangre* 23). In another moment, her colleague calls Lina on the phone while she is visiting Santiago. "¿Te olvidaste también de ti misma?, martilló Raquel intentando activar mi memoria o mi deseo de recordar. No la página sino la identidad que la sangre había asfixiado" (*Sangre* 83). Even the people closest to her have a feeling that she has changed character and that she has veered away from her previous identity. Almost at the end of the novel, Raquel speaks with Lina again. "¿Y la escritura?, me dijo, ¿qué tal va la escritura? ¿Qué escritura?, contesté yo, recordándole que por acuerdo mutuo yo había suspendido mi investigación. La enfermedad en la literatura latinoamericana, pensé pensando que yo era como la antropóloga que se enamora de su objeto de estudio" (*Sangre* 155).[11] Lina's world has turned upside down; even though she

---

[11] Lina Meruane, in fact, wrote her dissertation on AIDS, a work that was later published: *Viajes virales: la crisis del contagio global en la escritura del Sida* (2012).

does not use the exact word *disabled*, she appears to identify as such, due to the fact that she has converted into the object of her study. This change in her identity also reiterates the previously mentioned notion of a fluid identity ("Integrating" Garland-Thomson 33). In other words, our identities as human beings are ever-changing variables that transform with our lived experiences.

Furthermore, the reader can see that even in the relationship that Lina has with Ignacio she tends to represent herself as an ill woman as he takes care of her. In their essay, "Support Systems: *The Interface Between Individuals and Environments*," Simi Litvak and Alexandra Enders state that, "Medical and rehabilitation professionals, policymakers, and the general public, more than people with disabilities, often do not recognize how important integration and individuation of supports are" (2), which only creates more barriers for the disabled person. Even though Ignacio is a strong support system for Lina, their relationship seems to be more of a caretaker and a patient than two lovers. For example, Lina explains: "Ocho de la mañana de un lunes sofocante. Él se ducha después de prepararme con dedos torpes la jeringa y yo me inyecto la insulina antes de bañarme" (*Sangre* 35). Now blind, Lina is unable to even prepare her own insulin syringe, something that would affect her multiple times a day. At this point, Lina is very dependent on Ignacio, and before she returns to Santiago, Chile to see her family that still lives there, she begins to panic. Her dependence on Ignacio causes her to equate herself to a plant that grows and takes over its victim. She explains that:

> Ya no iba a tener sus brazos para guiarme, sus piernas para encaminarme, su voz para ponerme sobre alerta. No contaría con su vista para suplir la ausencia de la mía. Me quedaría aún más ciega. Supe que me había ido adosando a Ignacio como

> una hiedra, envolviéndolo y enredándolo con mis tentáculos, succionando de él como una ventosa empecinada en su víctima. (*Sangre* 50)

This guilt could possibly be explained by the notion of *deviance*. According to Darling, *deviance* is when "stigmatized individuals were expected to play a deviant role in society and would only be rewarded if they played the role that had been bestowed on them. Playing this role, in turn, reinforced a person's deviant identity" (34). Lina's new deviant role in her relationship with Ignacio begins to play a major part in her self-identity and further perpetuates her dependence on him. For example, her need for Ignacio and his healthy eyes transform into an erotic desire. While returning to New York, Lina narrates an event in which she stealthily separates Ignacio's eyelids while he is sleeping next to her and begins to pass her tongue on the inside of his eyes, describing her identification with the nude eye. Her erotic behavior continues, and soon she explains that she is sucking on his entire eye, making it her own "de un modo delicado, íntimo y secreto pero también apasionado" (*Sangre* 115) The object of her desire becomes the one thing that she no longer has: healthy eyes. This desire even propels her to ask Ignacio for his eyes, after finding out that her operation had failed, and telling him this would be the ultimate act of love. She explains, "eso que tú me entregarías nos uniría para siempre, nos iba a hacer iguales, nos volvería espejos el uno del otro, para el resto de la vida y hasta de la muerte" (*Sangre* 173).

In her essay "Blind Spot", Meruane confirms that there is a disputed authorship over the narration of Lina in *Sangre*. She states, that "Sometimes writing will require other eyes, but then the question arises: Where does the other's gaze leave off and one's own begin; where does Ignacio's body end and that of his blind woman begin" (30)? In other words, there is a dilemma with narrative authority because, in fact, Lina relies on Ignacio for what he sees, his reality and not her own. The closing of the novel is a scene in which Lina is once again at the office of the ophthalmologist. After hearing the news that he would not be able to complete a transplant because there were no eyes to use, Lina says to him, "No se mueva, doctor, susurré, espéreme aquí, yo le voy a traer un ojo fresco" (*Sangre* 177). Lina's fierce rejection of her new blindness, perhaps, is due to its sudden onset. In her book, Darling affirms that "another variable that seems to affect self-esteem is the timing of disability acquisition. L. Jemta and colleagues (2009) found that among the children and adolescents they studied, those with acquired impairments had lower global self-esteem than those whose impairments were congenital" (39). Lina's loss of vision was acquired as an adult, causing her identity to vacillate. Darling establishes that most adults that acquire a disability later on in life have a "strong identity as a nondisabled person" (129); therefore, many tend to struggle with this new identity. In *Sangre*, the reader witnesses just that; Lina wants to do everything that is possible in order to better her condition as a disabled woman.

In stark contrast to Lina's rejection of illness and disability in *Sangre*, in *Fruta*, Zoila takes pride in her illness as part of her identity. According to Darling, "Disability pride seems to include two aspects: self-esteem and separation" where the person with a disability celebrates their body and respects their individuality (94). This is exactly Zoila's outlook on the disabilities that her illness creates, as she rejects assimilation to an able-bodied world. In this sense, she aligns with feminist disability theory's standpoint of disability as "human variation rather than an inherent inferiority, a pathology to cure, or an undesirable trait to eliminate" (Garland-Thomson, "Feminist"1557). Throughout the plot, Zoila rebels against the attempts of her sister to control her diabetes. She affirms that "No podrá controlarme aunque lo intente. Mientras ella produce fruta perfecta en el campo yo produzco azúcar en mi cuerpo: en esta casa yo soy la encargada de mí, pero no como una madre abnegada ni como una laboriosa hermana rodeada de venenos. Mi empresa es la del descuido" (*Fruta* 42). She even goes as far as tampering with the results of her urine tests in order for her sister to stop bothering her and insisting on a transplant. Zoila states, "Esas son las botellas donde esa otra que yo soy, esa otra llamada Z.E.C., dona obedientemente su orina para el análisis microscópico de sus constantes embustes" (*Fruta* 58). As her illness progresses, it appears that it is now her identity, she views her diabetes as her own. In one scene she professes "La enfermedad es mía, no dejaré que me la quiten, le advierto" (*Fruta* 78). Again, the reader sees Zoila's rejection of a cure, and her acceptance of the illness now ravishing her body.

Further along in the novel, Zoila even begins to feel empowered by the detereoration of her body, and confesses that, "Estoy perfectamente, le digo aunque sé que no es cierto. Mi cuerpo empezará a capitular, más temprano que tarde. Debo apurarme: Mi vista siempre borrosa, los cada vez más frecuentes calambres en los pies me anuncian la ya inevitable disolución. Pero no tengo miedo, no siento angustia. Nunca me he sentido más dueña de mi cuerpo" (*Fruta* 101). Through this quote, the notion of disability pride is explicitly shown, as Zoila vehemently rejects the notion of a cure.

At the same time, Zoila even goes as so far to desire her own death. As she is waiting in the plaza by the hospital somewhere in the United States, she reflects on the fact that the end is near, with a deep happiness (*Fruta* 127). In this sense, she experiences a transcendence of her physical body, a notion that, according to Wendell, is often rejected by feminist theory (*The Rejected* 165). In her opinion, feminist theory about the body has not completely dealt with the disabled body and its experience, mainly due to the fact that feminism has always tried to change social arrangements that cause any kind of preventable suffering (*The Rejected* 166). In fact, in their book *Women with Disabilities: Essays in Pyschology, Culture, and Politics*, Michelle Fine and Adrienne Asch assert that disabled women have been characterized as childlike and helpless, severing them from the "sisterhood" so that feminism creates more appealing representation (4). So, how can the disabled woman fully integrate into society when the very group that should be representing her refuses to recognize her as equal part? Consequently, the representation of Zoila in Meruane's novel presents the reader with an ill and disabled woman who embraces her deteriorating body instead of rejecting it, and emphasizes the need for a renewed outlook of the typical able-bodied perspective.

Perhaps one of the most interesting aspects of Zoila's character and actions is a diary that she writes in called a *cuaderno deScomposición*.[12] As was previously mentioned, life-writing by people with illness and disability can help to better understand their experiences, emphasizing their subjectivity. In Zoila's journal, that Meruane leaves occasional traces of throughout the novel, she exposes her true feelings about her illness and her subsequent identification with it. Quite early along, the reader is introduced to the first entry of *cuaderno deScomposición*, that is loosely thrown into the text like poetry, without context. In this first entry, Zoila writes:

---

[12] In English it means *notebook of decomposition*. These writings in her diary are loose throughout the novel, with no context.

> vendrán los tiempos en que
> También
> Me descuelgue del mundo
> Cubierto de hongos
> Repleta de gusanos para rodar… (*Fruta* 33)

It is evident by this entry that she is aware of her decomposing body, and contemplates her mortality. In another section of her *cuaderno,* she compares her life to a long wait saturated with "consonantes y síntomas" and "notas conjeturales y pistas" (*Fruta* 55). Instead of a life in which she enjoys every day that she has, she is longingly waiting for her death, forced to go to medical appointments and endure treatment for her illness.

One of the last poetic entries in *cuaderno* comes after she encounters the Enfermera in the plaza outside of the great hospital. In this entry, Zoila reflects on her life while the Enfermera is speaking to her:

> Mientras hable no estaré sola
> Mientras me injerte adjetivos y adverbios
> Seguiré atrapada…
> Esperando que se calle para partir
> En una micro o en el metro
> En el camión extraviado del basural
> En la espléndida limusina del cementerio
> En el barco de carga de mis descargos… (*Fruta* 134)

Once again, the reader sees Zoila's desire to die and the tortuous wait that she must endure while this woman continues to talk. The lyrical entries in *cuaderno* also serve a different purpose, in my opinion. After reading the essay "Blind Spot", there was one section that resonated with me that had glaring correlation to the addition of *cuaderno* throughout the text. Not only is the protagonist performing a certain type of intertexual life-writing, but she is also breaking down the coherent organization of the novel. In "Blind Spot", Meruane exposes a similar pattern in her essay. She states that, upon writing the essay, her reflections turned more into a "disabled, fragmentary text" (38), similar to the *deScomposición* throughout the text of *Fruta*. By doing so, Meruane creates a text that, like the corporeal body, lives in a disabled, fragmented reality, many times passing in and out of disability identity. Meruane's text, in other words, as a body of text itself, questions the rules of normativity.

Social Experience and Marginalization

As was previously mentioned, disability theory framework examines the experiences of the subject with an impairment, and demonstrates how societal stereotypes perpetuate the notion of disability. Disability is a social construction in which able-bodied people support these stereotypes, which, in turn, may cause the person with an impairment to feel isolated. This isolation in society is then what causes the transformation of the impairment into a disability. According to Darling, the stigma of disability in society many times propels disabled persons to feel shame about their disability identity (9), although as seen in *Fruta*, some reject the medical model and embrace their impairment. However, throughout *Sangre*, the social experiences of Lina demonstrate the notion of stereotyping, as the reader sees her interactions with various people around her. At the beginning of the novel, Ignacio makes her feel bad about her new blindness, treating her like a child. He tells her, "Lina, suspiró, sumido en una tristeza o en una timidez repentina, Lina, aún más suave, sujetándome el mentón, sus ojos babosos por todas partes, estás ciega y eres una ciega peligrosa. Sí, respondí, con lentitud" (*Sangre* 29). In their article "Handicapism", Douglas Biklen and Robert Bogdan affirm that, "handicapped people are treated in ways that correspond to their stereotypes and are rewarded for living up to others' image of them…Thus they learn the role of the handicapped and fall victim to the self-fulfilling prophecies…"(5). After Ignacio speaks down to her, from this point forward the reader begins to notice the victimization of Lina and sees how the people around her now do not treat her like an able-bodied person.

In another scene, Lina mentions that due to her chronic illness, her family has always had to take care of her. While talking with them about her decision to do the ocular operation in the United States, she explains:

> Me reprochaban la decisión apresurada y acaso errada pero ya antigua de mis padres, la de sus treinta hasta entonces felices años, de regresar a Chile cuando yo. De suspender los planes que tenían cuando a mí. Y la frase se quedaba en vilo, incrustada entre los dientes de todos ellos. Nadie decía: esa enfermedad, la tuya. Nadie decía las pruebas, el diagnóstico, las inyecciones diarias, la dieta especial, el cuidado fatigoso de mi madre y la vida lejos del apoyo familiar. (*Sangre* 46)

Lina feels that she has always been a burden to her family because her diabetes forced them to have to take care of her. Once again, the person with an impairment is made to feel bad for suffering from an illness. It is not only the family that she has to confront, but also strangers at any place that she goes. In the plane on her way to Chile, Lina states that, "Yo no llevaba más que mi mochila con la jeringa lista para inyectarme; y eso hice, quitarle la tapa, pinchar la aguja donde cayera, presionar el embolo sin atender a los incómodos suspiros ajenos" (*Sangre* 53). Biklen and Bogdan also explain that social interactions between the able-bodied and those with an impairment can cause a lot of anxiety between both groups, because the able-bodied become more aware of the impairment of the other, causing them to focus on it (6). This provokes the abled-bodied to treat the impaired as different, thus perpetuating the stereotypes associated with having an impairment, and transforming this impairment into a disability. Said notion is evident in a scene in which a woman on the same plane as Lina begins to take not of her blindness. By accident, Lina touches the head of this woman, and at first, the woman gets mad. However, after seeing that she is blind, the woman begins to feel sorry for her. Lina describes the situation, "¿Ciega? La compasión me hacía crepitar de oído. ¡Ciega! Volvió a decir. Siéntese, insistió la mujer, pero yo no podía moverme. Me había paralizado esa piedad suya" (*Sangre* 56). This scene is a striking example of how many people with an impairment oftentimes refuse to identify themselves as disabled in order to save themselves from the devaluation of the able-bodied (Garland-Thomson, "Integrating" 35).

In comparison, even though in *Fruta* Zoila takes pride in her diabetes and firmly identities with it, her sister treats her as if she were a burden. Right from the beginning of the novel, Maria curses the day she was left to take care of her half-sister. In one of the opening scenes, she asserts, "En qué momento dejé que su Padre se largara al extranjero. En qué momento acepté hacerme cargo. En qué momento, qué desgracia" (*Fruta* 15). A little further along in the plot, after the diagnosis of Zoila's diabetes, María begins to show signs of *subjective burden*, a phenomena in which "disruptions in personal life and the responsibilities associated with the caregiving role often result in a feeling that one is carrying a heavy load" (Baronet 137). According to the Burden Assessment Scale by Reinhard, Gubman, Horwitz and Minsky, subjective burden can produce guilt, resentment and the feeling of being trapped (Baronet 138). It appears that in *Fruta*, María portrays some of these symptomatic behaviors categorized of subjective burden as she struggles to accept the illness of her sister. For example, the narrator states that, "María se levantó con nauseas: iba a tener una enfermedad metida dentro de su propia casa, la enfermedad se la había colado y no había manera de erradicarla" (*Fruta* 28). This obsession with destroying disease could stem from María's profession of fruit parasite exterminator; however, there could be an underlying fear of bodily variation. In her article, "Disability, Sex Radicalism, and Political Agency," Abby Wilkerson claims that, "Beneath the moral stigmas attached to pathologized bodies lies fear: the fear of bodily alteration, and even death itself—and to the extent that the singular human body represents the body politic, the fear of social upheaval and chaos, the loss of all social order" (193). Guerrero and Bouzaglo, like Wilkerson, argue that even when the illness is not contagious, it evokes sexual, racial, and political fears of the body (23). Therefore, is María's obsession at eradicating Zoila's illness the subconscious result of her fear of possible self-infection?

Even Zoila recognizes and pities the efforts of her sister to control the illness, and explains their current situation:

> No hay cómo extirpar la enfermedad que se ha instalado en la casa, murmura [María] agria una y otra vez. El mal es incurable, las complicaciones son severas: la compadezco. Ya la junta de médicos la escucha quejarse también compadecidos; la junta levanta los hombros, suelta un distraído no se preocupe, un quizá, un posiblemente algún día podamos ayudarla si es que la enferma colabora. Lo dicen con reticencia porque saben que me resisto, que mientras más estricto el control menos puedo cumplirlo. (*Fruta* 41)

According to Baronet, "Conceptually, one would assume that when care recipients exhibit a large number of behavior problems, caregivers and the family are likely to experience more disruptions. In turn, this may lead to greater feelings of subjective burden" (140). Consequently, Zoila's rebellion could be the cause of María's feelings of subjective burden, as she bitterly mumbles time and time again that the illness cannot be extirpated from her house. The medical discourse in which she participates with the group of doctors could be a possible outlet to manage her fear of the bodily chaos that has invaded her home.

Medical Pathology

The last aspect of disability studies that will be highlighted in this section is the pathologization of people with an impairment by the doctors that treat them. This is something that makes the impaired person feel as if their only identity was the impairment that they had. Current disability studies theory now places emphasis on the social factors that affect the notion of disability. The objective of this new social model is to liberate the disabled body from being seen as passive and pathologized, humanize the disabled subject from pathology and stereotyping, and reverse the social environments and structures that are disabling to the impaired body (Gleeson 74). Nevertheless, nowadays there is still a perpetuation of the language and treatment of doctors that affect the person with the impairment while promoting its pathologization. Throughout both *Sangre* and *Fruta,* the reader witnesses what disability theorists call *cognitive authority,* a term ascribed to the power of medical personnel to "describe and validate everyone's experience of the body" (Wendell, "Toward" 349). The doctors' pathologization of Lina's blindness and their obsession with a pancreatic transplant for Zoila ignores the women's own lived experience and appears to treat them as a mere test subject.[13] This cognitive authority fails to recognize the actual lived-experiences of the protagonists, something that breaks with the very essence of what feminist disability theory intends to prevent.

On one hand, the reader sees the medicalization and stoic behavior of Lina's ophthalmologist in *Sangre*. In one of the scenes in which Lina goes to his office, he is very short with her and even calls her vision situation a disaster. She states that the doctor, "se echó para atrás absolutamente resignado y dijo, habrá que esperar a ver si aclara y puedo echarle una vistazo a este desastre" (*Sangre* 43). He never remembers her name, nor those of his other patients, and he identities them only by the retinas that they have. At the end of the novel, after Lina finds out that her eyes cannot be fixed, the ophthalmologist explains the situation to her: "Hay venas en tu ojo izquierdo. Punto. Son venas nuevas. Punto. Pronto romperán la retina. Punto. Por ahora el otro ojo está quieto pero la sangre va a regresar. Punto. Vas a estar ciega dentro de nada. Stop. Era definitivo" (*Sangre* 176). In the above quote, one notices the lack of empathy of the doctor, and the pathology with which he appears to define her, aligning with the medical model of viewing disability, quite like Kleeges' experience of lack empathy and explanation from her doctor.[14]

---

[13] In her interview, Meruane states: "He estado trabajando literariamente la figura del enfermo y la del médico hace mucho tiempo; esto está ya en la novela anterior, *Fruta podrida*. Y de otro modo en mi investigación sobre el impacto del sida en la literatura, en *Viajes virales*. Es un tema que me importa a nivel personal pero sobre todo en el nivel político. Porque al margen de que hay médicos excepcionales, yo he tenido la suerte de conocer a muchos, y de poder huir de los otros, lo que hay detrás del médico es toda una institución poderosa ("Lina" n.p.)

[14] From *Sight Unseen:* "…when it was all over, my doctor named my disorder 'macular degeneration,' defined my level of impairment as legally blind, and told me that there was not treatment or cure, and no chance of improvement. At that was all" (Kleege 16).

Marja Mogk states that the medical model fosters “a clinical or institutional relationship to disability in which the focus is on the physiological cause, cure and care of impairment, all of which locate the problem of disability in a person and the solution in treatment and rehabilitation” (5). While it is important for medical personnel to accurately diagnose physiological maladies in a patient, it is also vital to recognize that this patient is a person with real feelings and lived-experiences. Instead of a dynamic in which the doctor acknowledges what Lina is going through, he only highlights the disparity of the medical situation and construes her disability as simply pathological.

Although medical pathologization appears in *Sangre* at a minor level, in *Fruta*, on the other hand, Meruane focuses this notion as one of the main themes. There are various characters throughout the narrative that exhibit medicalization and cognitive authority, such as el Médico, el Enfermero, and la Enfermera.[15] At the same time, the reader witnesses Zoila’s rebellion against this pathologization and cognitive authority, and Meruane exposes the reality of the financial chain of the medical industry influenced by the State.

In her work, *Critique of Postcolonial Reason*, Gaytri Spivak discusses the placement of the third-world postcolonial woman in the patriarchal State, and affirms that “the figure of the woman disappears, not into a pristine nothingness, but into a violent shuttling that is the displaced figuration of the ‘third-world’ woman caught between tradition and modernization, culturalism and development” (304). These “displaced women” are what disrupts the patriarchal state, causing their rejection and propelling the

---

[15] Interestingly enough, in *Fruta* all medical professionals do not have a name, and are called by the profession that they have, perhaps to place all subjectivity on the two main female protagonists.

State to correct what is threatening, including the disabled woman. According to Cindy Lacom in her article "Revising the Subject: Disability as 'Third Dimension' in *Clear Light of Day* and *You Have Come Back"*, what we see in these postcolonial nations is that "status quo is tentative, fluid, and subject to constant revision and that "out of bound" bodies foster that revisionary process in important, even radical, ways" (170). This "revisionary process" can be seen in *Fruta* with the ill character Zoila, who, with her "out of bound" body, has the potential to disrupt the totality of the able-bodied patriarchal State, something that Lacom argues occurs with any disabled character (171).

The revisionary process of containing "out of bound" bodies aligns with the medical pathologization and medicalization seen in *Fruta*. Throughout the plot, there seems to be an obsession with curing Zoila and her illness. For example, during the initial diagnosis of type 1 diabetes by el Médico, María is worried that her sister will die, and el Médico scoffs at her concern: "Su hermana a medias, ¿morirse?, repitió el Médico palideciendo aún más y balbuceó: morirse nadie. Sobre mi cadáver se morirá alguien en este hospital. Para qué cree que estamos trayendo tanta máquina, tanta tecnología importada contra la muerte" (*Fruta* Meruane 23), and that even if they are unable to cure Zoila, the operations will contribute to the development of science and the futile illusion of others (*Fruta* 27). According to Simi Linton in her book *Claiming Disability: Knowledge and Identity* (1998), this obsession and medicalization against unruly bodies "casts human variation as deviance from the norm, as pathological condition, as deficit, and, significantly, as an individual burden and personal tragedy" (11). She goes on to say that assigning medical meaning to any type of impairment or disability only treats the person and condition rather than social processes and policies (11). This only leads to further isolation of the impaired, and perpetuates the social creation of disability. In Zoila's case, she is made to feel as if the medical treatment and attempted curation of her type 1 diabetes is a privilege, even though she does not see her illness as a problem. In one instance, El Enfermero that takes care of her argues that she should be thankful for his help and that she needs to thank him for explaining:

> el funcionamiento del cuerpo y su deterioro final, por recordarme que debía agradecer haber sobrevivido a la enfermedad, por seguir viva pese a todo, por tener a alguien que había estado dispuesta a entregar a sus propios hijos por colaborar con la ciencia y salvarme. Agradecer, sí, cada maldito día, porque en otros tiempos, la gente como yo resistía apenas unas semanas, a duras penas una quincena…Que agradezca haber sido privilegiada, premiada por la ruleta perversa de la medicina que alarga sin sentido mi inexorable deterioro. (*Fruta* 97)

From the above quote (and as demonstrated previously), the reader can see that Zoila does not desire a cure; she actually resents the medicine that is keeping her alive. Although in *Fruta* the reader witnesses the notion of pathology in the attempted management of type 1 diabetes, what Meruane accomplishes through Zoila's character is actually the devaluation of medical diagnosis and interpretation by rejecting treatment and placing emphasis on her own depathologized experience.

Perhaps the most striking example of Zoila's rebelling against medical pathologization is not her refusal of treatment, but rather when she begins to cut off the life support of many patients at a hospital in the United States. Although the exact location is unknown, Zoila describes her attack, now using second person. According to Mieke Bal in her book *Narratology: Introduction to the Theory of Narrative* (1985), "the ‘you’ is cut off from the others, or cuts them off, so that, rather than mutually confirming one another’s subjectivity, the figure of this ‘you’ lapses into an autistic monologism. The pronoun ‘you’ becomes a reminder of the alienation, that recession of subjectivity, rather than a fulfillment of it” (30). However, rather than a negative connotation of isolation, perhaps Zoila talks in second person to cut herself out of society’s pathological view of illness. Zoila describes her attack, explaining that there are so many wires to cut in the hospital where doctors and surgeons work day and night keeping patients hooked up, drugged, and experimented on, sentenced to live out their life without being able to choose (*Fruta* 129). It is clear she rejects medicalization in hopes of giving subjectivity back to the patients, instead of being labeled as a pathological object of the doctors. Once seeing the myriad of children who had no life outside of the hospital, Zoila begins to cut cannula after cannula in an effort to halt the chain of pathologization:

> Vas asomándote en el silencio de las salas hasta que de pronto, ahí están. Son ellos, ahí, amarrados a sus camas, conectados a una sola gran botella llena de líquido que se distribuye en lentas pero exactas gotas hacia sus venas. ¿Quiénes son estos niños, con qué promesa falsa los han encerrado en esta sala, intervenido con mangueras, monitores y pulseritas blancas? ¿Cuántos datos de interés científico han extraído de su sangre, qué les han extirpado y quién los reciclará y dónde? ¿Para qué quieren mejorarlos, si están todos condenados? Les han arrebatado la posibilidad de decidir, de ser dueños de su propio destino, y una rabia antigua se posesiona de ti, de tus manos, de tu impaciente tijera. (*Fruta* 132)

It appears that Zoila’s attack is more about the liberation of the disabled subject from western scientific-medical culture, something that, as Wendell explains, dismisses the lived perspectives of the disabled, and focuses on "a model of temporary illness, total recover, and complete return to the former self" (*The Rejected* 68). Because Zoila feels as if she was forced into medical treatment of her type 1 diabetes, it seems that her devious actions stem from her desire to free others who are in a similar situation.

In her article, "The Color of Violence: Reflecting on Gender, Race, and Disability in Wartime," Nirmala Erevelles states that many times in these postcolonial patriarchal states, women are "seen as essential to the biological, social, and cultural reproduction of national identity" and that they "are often subject to the close scrutiny of the normalizing regime of the nation-state" (121). Erevelles also affirms that women who deviate from the ideological norms of the patriarchal state are rejected in society and seen as abnormal (122), a possible reason for the obsession of medical pathology and the curation of unruly bodies. This rings true in *Fruta*, seen in the numerous attempts by the medical professionals that treat Zoila. However, el Médico takes medical pathology to a new level when he asks María to pay for Zoila's treatment through "donaciones anuales a la ciencia" while keeping his eyes fixated on her belly (*Fruta* 29). This extortion comes as no surprise to Zoila who, in the narrative, refuses to be "parte de esa cadena…en la que…participaban las frutas del campo y también los frutos…los frutos del propio cuerpo de la hermana" (*Fruta* 172). She recognizes the corruption of the medical field, calling it an assembly line of productions (130); this production extorts and oppresses the poor disabled female (Erevelles 116).

Furthermore, after Zoila meets La Enfermera[16] in a plaza outside of the attacked hospital, the reader notes the stress placed by Meruane on the future of medicalization and pathology. La Enfermera states that medical professionals love life, that they love "las guaguas de probeta más y más, la inmortalidad de los transplantes, la clonación terapéutica y también regenerativa con células madre" (*Fruta* 149). This obsession with treating medical maladies corresponds with the medical model of viewing illness and disability in its attempts to cure and mitigate the threat of the unruly body. La Enfermera explains to Zoila that the scientific, financial, and international bodies of the State are all united by "cordones umbilicales" (*Fruta* 149) and that it would be better to adjust to the theme of transplants because human existence resides in a future of "prolongación" and "repetición eterna" (*Fruta* 164). La Enfermera describes the harvest of organs from the ill or disabled patients: "ahora almacenamos a los muertos, los bañamos, los afeitamos, les escobillamos los dientes y tras empolvarlos los guardamos. Sus cuerpos deben quedarse por si el corazón, por si el hígado, por si las córneas sirven para algo" (164). She also claims that a person's body is the collective property of the society in which it lives, that their *body* belongs to the State. This aligns with the opinion of Erevelles, who affirms that "the neocolonial state is implicated in of the pathologization disability" (123). La Enfermera also suggests that whatever cannot be cured by science today will be cured with time (*Fruta* 174). In response to the argument of La Enfermera, Zoila contests, "¿Y si el tiempo fuera la herida, una herida que con el tiempo se infecta?" (*Fruta* 175). This statement proves Zoila's state of identity and her viewpoint on the medicalization of

---

[16] La Enfermera works at the hospital that Zoila attacked. She explains that these attacks had been happening for ten years (*Fruta* 147).

illness and disability; she opposes the continuous notion of a cure. In fact, Zoila insinuates that the attacker of the hospital was a woman that:

> ha sido privilegiada con un cuerpo enfermo, un cuerpo que se va destruyendo a sí mismo; sugiera que esa circunstancia la dispensó de trabajar…Esa mujer nunca produjo nada, sólo una infinita cantidad de frustraciones y de malestares para la hermana que por años estuvo a cargo de cuidarla Esa hermana suya se había obstinado en encontrar la fórmula para curarla. (*Fruta* 172)[17]

Zoila's statement suggests that she believes she was privileged because of her ill body. This challenges popular notions of the ill woman's body as "inferior, lacking, excessive, incapable, unfit, and useless" (Garland Thomson, "Feminist" 1567). Therefore, Meruane's depiction of Zoila and the disability pride that she has of her ill body situates the disability experience as an interpretation of human variation rather than a pathological condition to eliminate.

Conclusions

In his article, Gleeson explains that "The inclusion of work on chronic illness, ageing, obesity, and new biotechnologies broadens the lens of recent inquiry and thus links disablement to the broader and necessary notion of human frailty and the shifting lines of social response (75). Disability studies, although scarcely applied to Chilean cultural products, is extremely beneficial in opening up a dialogue about the disabled subject as a marginalized group and placing emphasis on their subjectivity. As previously mentioned, one way to improve discourse on disability and understanding its construction

---

[17] At this point in the narrative, the reader is aware that Zoila is the attacker, but La Enfermera still does not know.

is through the life-writing of people living with one. Lina Meruane does exactly that in *Sangre en el ojo* and *Fruta podrida*. Both of Meruane's narratives demonstrate and explain the devastating effects that type 1 diabetes can produce, causing the protagonist's blindness in *Sangre* and the near death experience of Zoila in *Fruta*. The two narratives, while showing the daily struggles that both protagonists face, have different foci. While in *Sangre* the protagonist Lina rejects her status as a disabled woman and loses her identity, in *Fruta* the protagonist Zoila identifies with her illness and disability, and rejects the popular notion of finding a cure.

Furthermore, both narratives exemplify the negative behavior of able-bodied people, something that only adds to their feeling of isolation and difference. In the words of Álvarez-Martín y Neves Silva:

> se comprende que el concepto de personas con discapacidad no pasa apenas por la presencia de una deficiencia, pero también, en la forma de relación de las personas con el ambiente y la sociedad. Una deficiencia puede generar una discapacidad si la persona no consigue participar de las actividades sociales de manera inclusiva, pero cuando el ambiente se encuentra preparado para recibir las diferencias una persona con deficiencia puede no ser incapaz. El concepto de discapacidad incluye la relación de la persona con el medio en que vive y la estructura social que está insertada. (4894)

How can chronically ill and disabled people completely integrate themselves into society when they are continuously marginalized, perpetuated by stereotypes, the feeling of inferiority, and the stoic pathologization of doctors? Applying feminist disability theoretical framework can, at least, open up a necessary discourse about the chronically ill disabled subject, and how disablement is constructed in society, something *Sangre en el ojo* and *Fruta podrida* effectively accomplish.

CHAPTER 3

FEMININE CORPOREAL DETERIORATION AND LITERARY CATHARSIS IN *DIARIO DEL DOLOR* BY MARÍA LUISA PUGA, *CLAVÍCULA* BY MARTA SANZ AND *DIARIO DE UNA PASAJERA* BY ÁGATA GLIGO

Traditionally in history, Woman has been placed at a marginalized position in society by delegation of the patriarchy. Therefore, it comes as no surprise that when it comes to the disabled woman, a double marginalization emerges: being a woman and being disabled. In her book *The Second Sex* (1949), Simone de Beauvior describes the historical relationship between man and woman, and argues that while man thinks of his body as normal, he regards the woman's body as a "hindrance, a prison, weighed down by everything peculiar to it" (xvi). In her work, de Beauvior plants the notion of the Other, where man considers himself the Subject/Absolute, and woman is thought as the Other (*The Second* xvi). Renowned feminist disability theorist Rosmarie Garland-Thomson takes Beauvior's idea a step further, connecting this Otherness with the typical representation of the female body as disabled. She indicates that, historically, women were known as the fairer of the sexes, oftentimes denominated as crazy, fragile, helpless, weak, vulnerable, dependent, and incapable bodies (Garland-Thomson 19). Indeed, this portrayal has been wrongfully associated with Woman throughout history, cohesive to the political and societal norms of the patriarch. In her essay "Integrating Disability, Transforming Feminist Theory", Garland-Thomson states that using feminist disability theory can provide a deep analysis of the medicalization of the female body in current society. She goes on by explaining that disabled people and women have been designated as weak and medically atypical, and that "Sickness is gendered feminine. This gendering of illness has entailed distinct consequences in everything from epidemiology and diagnosis to prophylaxis and therapeutics (Garland-Thomson, "Integrating" 22). In other words, the ill/disabled woman is doubly marginalized, both due to her gender and also her disabled status.

This gendering of illness creates a stigma for women, causing them to many times be treated differently by the doctors who evaluate them and the people in their environment. In *Clavícula*, *Diario del dolor*, and *Diario de una pasajera*, we see the daily struggle in the autobiographical episodes of all three authors, Sanz dealing with an unknown illness, Puga with rheumatoid arthritis, and Gligo with cancer. Throughout their lived-experiences as ill/disabled women, they must deal with the pathologization of their illness[18] and present unique views on how they handle their pain, their interactions with medical professionals, and the impairment that their illnesses cause them in everyday life, a struggle they handle by using writing as a cathartic tool.

In her book *Unruly Bodies: Life Writing by Women with Disabilities* (2007), Susannah B. Mintz exposes the benefits of life-writing used as a cathartic tool that contests defining disability through medical discourse, and shifts importance to the embodied position from which a disabled woman may choose to narrate her own life experience (17). In many cases, she explains, these autobiographies tend to reject the "stereotypical rhetorical patterns" that generally the able-bodied can identify, such as, for example, a tale of the disabled hero (17). Similarly, in her book *Female Forms: Experiencing and Understanding Disability* (1999), Carol Thomas emphasizes the

---

[18] In *Clavícula*, both doctors and friends attribute the protagonist's relentless pain to menopause and anxiety. In *Diario del dolor*, doctors tell her Puga she must adapt to her chronic illness and use of a wheelchair.

importance of life-writing, and illustrates the connection of gendering disablism as feminine by providing examples of such writing. In her opinion, “the effect of using women’s personal narratives is to simultaneously draw attention to the ‘ordinariness’ of many of these women’s lives”, in hopes to reject the “Otherness” of disabled females (Thomas 99). At the same time, she argues that life-narratives by disabled women help to illustrate and illuminate the various social barriers that these women may face (Thomas 30).

However, when drawing upon and analyzing such life-writing, it is vital to recognize the intersectionality of disabled women, keeping in mind various factors such as age, race, nationality, and social class, amongst others, which create different lived-experiences. By doing so, one avoids over-generalization and the attribution of universalistic qualities to disabled women (Thomas 99). One of these intersections, as previously mentioned, is age. According to de Beauvior, whereas man has a smooth transition between the various stages of his life, women have transitions that produce crisis, such as puberty and menopause (*Second* 575). She continues by stating that, “Whereas man grows old gradually, woman is suddenly deprived of her femininity; she is still relatively young when she loses the erotic attractiveness and the fertility which, in the view of society and in her own, provide the justification of her existence and her opportunity for happiness” (de Beauvior, *Second*, 575). While many women nowadays may not put all their happiness in fertility and attractiveness, society still focuses on the negative consequences of aging. Therefore, age plays a substantial role in the intersectionality of both abled and disabled women, and causes a broad range of stereotyping that tend to represent the aging female as undervalued, underrepresented, and undersexed (Mintz 184). According to Mintz, this problematized depiction of older women, however, can be combatted by writing life-narratives. These life narratives serve both as a cathartic tool for the aging woman and an instrument to bring about awareness of the connection between aging and impairment/disability.

In her essay, "Unhealthy Disabled: Treating Chronic Illnesses as Disabilities," (2001), Susan Wendell discusses how age can impact the social category for which an ill or disabled woman is associated. She argues that younger and middle-aged women with chronic illnesses are, "too young to be ill for the rest of [their] lives, yet [they] are not expecting cure or recovery" (21). What this creates is an in-between status for the middle-aged ill woman, producing both an organic and mental crisis. This in-between status then situates the middle-aged disabled woman in the margins, many times ignored or belittled by the medical personnel that treat them, attributing their illness to hysteria or menopause. Mintz confirms that time and again "the physical and cognitive shifts associated with aging become the unacknowledged, because feared, potential of human corporeal existence, at the same time giving the lie to the fetishized body of ableist culture" (183). How can chronically ill and disabled middle-aged women, then, be acknowledged in current society when the doctors that are treating them diminish their experiences?

Throughout the three life-narratives in question, *Diario del dolor*, *Clavícula*, and *Diario de una pasajera*, the reader witnesses the juxtaposed binaries of able/disabled, healthy/sick, and youth/aging in the very real subjective experiences of Puga, Sanz, and Gligo. We see how each must come to terms with their illness and subsequent disability as a middle-aged woman, all using literary catharsis to validate their experiences and make sense of the pain that they are suffering. Consequently, in this chapter I delve into an analysis by first discussing the realization of life-writing as a cathartic tool in the disability experience, and then investigating the engenderment of illness and disability, stressing female corporeal deterioration over the longue durée and the problematic universalization of the menopausal ill or disabled woman by the doctors that treat them.

Literary Catharsis and Subjective Experiences

In her work titled, *On Being Ill* (1930), Virginia Woolf argues that while writing about the mind is a prime theme in literature, the body tends to be ignored (5). In *On Being Ill* and her famous *The Diary of Virginia Woolf*, Woolf discusses her health crisis and months of illness, and Hermione Lee confirms that Woolf's life-writing on illness emphasizes "its [writing] creative and liberating effects" (xiv). Arguably one of the most famous *ill* women in literary discourse, Woolf's life was riddled with headaches, fevers, faints, insomnia, and depression, common themes even in her fictional work (Lee xii). Even Woolf, some eighty-five years ago, recognized the cathartic value of writing about the illnesses from which she was suffering.

Therefore, it comes as no surprise that with an increase of feminist and corporeal studies that autobiographical life-writing of illness has surged in the last thirty years, taking part "in this larger pattern of storytelling that directly eschews presumption of a fully accessible, distinct but also representative subject" (Mintz 7). This life-writing by women with disabilities is cathartic in the sense that it converts them from a passive invalidated object into an active subject who is in control of the text. As aforementioned, in *Diario del dolor*, *Diario de una pasajera,* and *Clavícula*, each female author explains her subjective experience with illness and a decline in her corporeal health. In order to discuss these experiences, all three authors describe the importance of writing to them in their journey of deteriorating health, and how this writing has therapeutic value to their recovery and/or disability acceptance.

Throughout these autobiographical narratives, writing is seen as a tool to discussing, confronting, and overcoming their experiences of both chronic illness, and anxiety and depression.[19] As was previously mentioned, all three authors are middle-aged [20]— Sanz at 47 years old, Puga at 58 years old, and Gligo at 56 years old,—and must face crippling illness and disease as they struggle to cope with the change in their bodies and the stereotyping of a menopausal woman. Their life-writing is used as a type of therapy, a tool that Smith and Watson confirm aids in the healing of the body. In their book, they state that, according to medicine and bioethics, narrative therapy (telling) and healing are "integrally linked", as they promote survival, transformation, and recovery, and at the same time help in the acceptance of their dying body (226). Part of these autobiographical narratives of acceptance and survival is the organization of social spaces, driven by relationships and actions with others in their environment (Smith and Watson 44). In turn, these relationships are formalized through "gesture and bodily positioning" (Smith and Watson 44). To reiterate, current disability studies places emphasis on the social experience of the disabled person, as this helps to situate them as a subject and not a pathologized object. Nonetheless, the fact that the disabled body is

---

[19] In her document "The Menopause Experience: A Woman's Perspective" (2002), Sharon George states that anxiety and depression are possible psychiatric illnesses associated with premenopausal and menopausal women (78).

[20] The term middle-aged is different now than in the time of Woolf and Beauvoir. According to statistics in an article written by Max Roser titled, "Life Expectancy," the average life-span in the Americas and Europe in the early 1900's was around 42 years old (n.p.). This is about half of the current life expectancy of 2018, which is about 72-80 (n.p.).

placed in relationship to the nondisabled body, such as the female to the male, only leads to the development of “sexist medical models that pathologize female bodily functions, such as pregnancy and menopause, and exclude women research studies” (Samuels 55). Therefore, the writing and publication of life-narratives, as Smith and Watson affirm, are forms of “self-reinvention” as they go through their journey of illness, diagnosis and treatment (141).

Similarly, in *Recovering Bodies: Illness, Disability, and Life-Writing* (1997), G. Thomas Couser depicts the term *autopathography*, a word that he uses to describe an autobiographical narrative of disability or illness. Couser explains that in *autopathographies,* facing an identity crisis is typical with the onset of illness or disability, causing the person to self-reflect. According to Couser, in these *autopathographies*, bodily deterioration may heighten “one's awareness of one's mortality, threatening one's sense of identity, and disrupting the apparent plot of one's life” (*Recovering* 5). This “disruption” causes the *autopathographer* to reflect on their new life with the illness or disability and their subsequent status in society. Not only are they forced to deal with their corporeal deterioration, but they are also forced to reinvent themselves in society.

In summary, Mintz, Couser, and Smith and Watson, amongst others, all agree that life-writing about illness or disability proves to be beneficial in the confrontation and treatment of the disabled body or mind. Not only does this type of life-writing force the author to face their own newly found ill or disabled identities, but it is a form of self-expression and a means to deal with the deterioration of their bodies and the marginalized status that they are now experiencing, all themes exemplified in the works of Sanz, Puga, and Gligo.

Clavícula

Right from the beginning of *Clavícula*, Sanz begins to describe her battle with an overall feeling of malaise, beginning in her clavicle during a flight. Throughout her narration, she explains the development of her illness, the opinions of doctors and friends, and describes her preoccupations with dying and the subsequent anxiety that it causes her. In her efforts to feel better, Sanz writes about her experiences with her unexplained illness, and many times reflects on the healing power that writing gives her. She explains that her autobiography is a consecration of reality, even though it makes her fearful (292).[21]This consecration of reality is an "inter-subjective exchange between narrator and reader" that produces a shared understanding of life (Smith and Watson 16). This inter-subjective exchange validates the author's experiences as the reader begins to understand her life. In one of the first reflections of her life-writing, Sanz states:

> «Escribo de lo que me duele.» Lo repito en cinco, en diez, en doscientas entrevistas. «Escribo de lo que me duele.» Hoy veo con toda claridad que la escritura quiere poner nombre e imponer un protocolo al caos. Al caos de la naturaleza, a la desorganización de esas células dementes que se resisten a morir, y al caos que habita en el orden de ciertas estructuras sociales. La escritura araña la entropía como una cucharilla de café el muro de la prisión. Amputa miembros. Identifica—para sanarlas—las lacras de la enfermedad. (295)

---

[21] The version of *Clavícula* that is used is a Kindle edition. Therefore the number I use refers to the line location in the Kindle version.

For Sanz, writing is a cure for the bodily chaos that she is feeling, and has a certain healing nature. Writing, in other words, helps her to pinpoint her illness in hopes of identifying and curing it. She also states that, upon writing this narrative, she is purging herself, as she believes in “la posibilidad catártica de la escritura” (1126). This purging is what Richard Kearney discusses in his article “Narrating Pain: The Power of Catharsis”, recounting the words of Aristotle that the function of *catharsis* is literally the purgation of pity and fear (51). Kearney argues that catharsis is a release from the pain, trauma, or suffering that the narrator is going through (61), or as he calls it, “a labour of recognition” (63). Throughout *Clavícula* the reader witnesses Sanz’s “labour of recognition” of her deteriorating and aging body, as she attempts to figure out the cause of her pain.

At the same time, Sanz contemplates the process of writing her autobiography and speaks in plural for all women writers, creating a social collective. In her essay, “Plural Singularities: The Disability Community in Life-Writing Texts”, Margaret Rose Torrell argues that, “autobiography by women tends to tell the story of an identity that is relational and gestures toward community” (324), a community that is strengthened when the singular voice calls forth to others (325). This feminist social collective that Sanz creates represents a paradigm over the typical patriarchal representation of gender roles. The use of the *we* form recognizes the female sex as a whole, although she does clarify the intersectionality of the female identity. In one instance she reflects on the possible reasons behind the chosen topics of their writing, and while doing so, makes it clear that even though they may have some things in common, not all of their life-writing is equal:

> Recogemos una inquietud de época y escribimos estas cosas porque algo nos duele, porque somos mujeres, porque tenemos o no tenemos pareja, escribimos,

> tenemos y no tenemos trabajo, somos españolas y blancas, posiblemente feministas, posiblemente de izquierdas. Pero nuestros libros no están escritos con las mismas palabras y, en consecuencia, no, no son iguales. (Sanz 185-87)

What Sanz is saying, in other words, is that while women may fall into the same category solely based on their sex, not all women will write about the same topics. This recognition of intersectionality, even strictly within the Spanish population, represents the autobiographer's autonomy and authorial claim to her subjective, individual lived-experience. Similarly, a little further along, Sanz once again speaks in the first person plural, the collective *I,* as she talks about autobiographies in general. She explains that when a person writes, they are unable to forget their physical conditions and materiality. Therefore, she states, many times autobiographical texts are more truthful than an in-person declaration (Sanz 288). Along the same lines of this statement by Sanz, in their work Smith and Watson argue that, "Any utterance in an autobiographical text, even if inaccurate or distorted, is a characterization of its writer" (6-7). Thus, the writer, through the very process of rewriting her/his lived-experience, presents a characterization of her/himself in every aspect of the text, a veracious self-representation. Not only does Sanz write about her own subjective lived experience, but she also represents other middle-aged women suffering from some form of disability.

In addition, the reader finds bits and pieces of intertextuality throughout *Clavícula,* as Sanz provides excerpts of fiction that she had previously written. As she reflects on one of the stories she wrote a few years back about a menopausal woman, she realizes that she is now living through the same period of life (129). In another example, she describes a different character named Luz Arranz, who, in a diary, talks about the transformation of her anatomy (Sanz 136). In these two examples, we see a mirroring effect of the notion of the Other, in this case a woman’s view of herself and her changing body portrayed in the characters that she has created. What I mean by this, is that by depicting these two characters as menopausal women, Sanz is able to reflect on the Othering of her own menopausal experience. In other words, as Wendell argues, “When we make people ‘Other’, we group them together as objects of our experience with whom we might identify, and we see them primarily as symbolic of something else—usually, but not always, something we reject and fear and project onto them” (*Rejected* 60). In the case of Sanz, the fear of her own menopausal self is symbolized through these characters, although she now realizes she, too, has begun that stage of her life.

Towards the end of her life-narrative, Sanz explains that the previous pages describe a process and talk about a person (1211), a statement that emphasizes her awareness as subject. According to Smith and Watson, this process of telling one’s story “is not a passive one of mere retrieval from a memory bank (22). Rather, the remembering subject actively creates the meaning of the past in the act of remembering” (Smith and Watson 22). While narrating the events that took place, Sanz takes on an active role in the telling of her life, of remembering. Furthermore, her affirmation that what she narrated is about a person and not “pasos del baile” (Sanz 1226) is also a strong declaration of her subjective experience. This declaration places emphasis on the embodiment of her lived-experiences, and perhaps, as Stacy Simplican posits, is a tool to empower her to “counter sexual and ableist marginalization” (48) that she now faces with her new ill/disabled body, a theme that will be discussed in the second section of this chapter.

Diario del dolor

While Puga also delineates her health struggle throughout *Diario del dolor*, she shares that she suffers from a chronic illness, rheumatoid arthritis, which causes her to live in constant pain. According to the Mayo Clinic, rheumatoid arthritis:

> …is a chronic inflammatory disorder that can affect more than just your joints. In some people, the condition also can damage a wide variety of body systems, including the skin, eyes, lungs, heart and blood vessels. Unlike the wear-and-tear damage of osteoarthritis, rheumatoid arthritis affects the lining of your joints, causing a painful swelling that can eventually result in bone erosion and joint deformity. ("Rheumatoid" n.p.)

Rheumatoid arthritis is, like type 1 diabetes discussed in Chapter 1, an autoimmune disease in which your immune system attacks your own body, tissue, and organs ("Rheumatoid"), leaving its victim in debilitating pain. Interestingly enough, women are more likely to develop this illness instead of men, most commonly between the ages of 40-60 ("Rheumatoid").

Because of the great pain that she experiences on a daily basis due to her rheumatoid arthritis, Puga decides to start a diary and chronicle her experience. In fact, the pain she suffers plays a protagonist in her life, and she talks about Dolor as if it were a person, perhaps as a way to confront her newly disabled status. Throughout the diary of her pain, Puga, like Sanz, talks about her experience with doctors, as well as her social interactions and ability to fit into an able-bodied world. She does all of this through one-hundred titled diary entries, in comparison to the more novelistic style of Sanz. Throughout the diary, the reader encounters Puga's self-reflection as she contemplates her writing and its importance in the journey of her illness. Much like the characterization of Dolor, Puga talks about writing as if it were a character.[22]

In one of the first instances in which *escritura* appears, Puga states, "Es la escritura que me pregunta: ¿Te vas a curar?" (20) to which she responds: "Me costó tanto trabajo aprender a ser así que creo que no tengo fuerzas para aprender otra forma. Eso le digo a la escritura porque en realidad es ella la que no encuentra palabras para hablar de una posible realidad curada" (20). Perhaps what is happening here is cognitive dissonance, a common occurrence amongst people who become disabled, a notion that Erin Martz talks about in her article "A Philosophical Perspective to Confront Disability Stigmatization and Promote Adaptation to Disability." According to the *Encyclopedia Britannica*, cognitive dissonance is defined as "the mental conflict that occurs when beliefs or assumptions are contradicted by new information" ("Cognitive" n.p.). Therefore, Martz connects cognitive dissonance to the dynamics of chronic illness or disability, in which the individual that suddenly loses some type of bodily function struggles with this new information about their body (142). In *Diario del dolor,* the reader witnesses cognitive dissonance in Puga's identity as she goes in between her disabled state and the possibility of healing. Much like Nancy Mairs' questioning her identity outside of Multiple Sclerosis in her autobiographical work *Waist-High in the World* (1997), Puga searches for meaning outside of her new identity with rheumatoid arthritis. This cognitive dissonance, according to Martz, can cause a type of existential crisis (142), something that appears to be affecting Puga as she struggles to both accept Dolor and the possibility of cure.

---

[22] It is worth noting that while *Dolor* is capitalized, *escritura* is not.

Nevertheless, Puga's existential crisis appears to be reversed as she fears cure instead of her disabled state. In order to purge her fears of a cure, Puga grants a voice to *escritura* in which she projects these fears of reverting back to an able-bodied woman and what that may entail. In doing so, Puga exemplifies the affirmation of Smith and Watson that the narrator, in cases of diaries, can be addressing another version of herself (88-9). Also exemplifying this notion comes in the entry titled "33. La escritura exige" in which Puga discusses how *escritura* begins to talk to her, asking her to reflect on her new identity of living with Dolor (32). Now living with a chronic illness, Puga is unable to return to the life that she once knew; she becomes a different version of her previous self. Being able to write while in this new position as a chronically ill and disabled woman, Puga, like many disability autobiographers explains, is able to counter her marginalized position as a pathologized object, and transform herself into a material subject, like Couser explains in *Signifying* (7). In this sense, writing serves as an outlet from her objectified ill body, and functions as a tool to revert back into a body in control.

Furthermore, in the same entry Puga explains that many times while she is writing, Dolor "asoma su escuálida cabeza de pelos grasientos y mira con atención" (34-35). This unsettling personification of Dolor is both a recognition and affirmation of the malignant role it plays in her life, describing him as having an emaciated face with greasy hair. Following this personification, she continues by stating that Dolor does not like when she writes in her notebook, even though it is necessary for her to write about her hospitalization and operation in order to not disappear in this parallel reality of self-identification (Puga 36). In *The Rejected Body*, Susan Wendell, much like Puga, discusses how chronic illness and pain led her to a transformation in identity (175), one in which she was forced to adjust to a disabled status. Wendell also sustains that many people living with pain either accept it, give in to it, or observe it in efforts to alleviate suffering. She states that many times they define this as "making friends with their pain" (Wendell, *Rejected* 171). By creating Dolor as a main protagonist in her diary, Puga seems to be doing exactly what Wendell delineates. However, in my opinion, it seems that instead of "making friends" with the pain she is suffering, Puga confronts it by recognizing its existence in her daily life. For example, while at a conference on the territories of violence in Monterrey, Puga talks directly to Dolor. She states:

> No es un tema que te pueda ser indiferente. Te veo asombrado. Nunca creíste que se podía hablar tanto y en tantos tonos de ti… ¿No sentiste que ya lo habías oído todo? Si yo lo sentí, que sí tengo edad, tú te habrás dado cuenta de inmediato: van a hablar de mí. A lo mejor nunca te habían traído a un Encuentro de Escritores que te tuviera a ti como tema, unido a la escritura, a la creación literaria. Nunca te llevaron a nada, Dolor, porque estás presente en todo. (73)

In this quote, Puga both recognizes the omnipresence of Dolor, such as in suicides caused by its existence, and connects Dolor to her writing and all literary creation. In this sense, like Wendell's affirmation of disability acceptance, Puga accepts its presence.

According to Wendell, pain makes us rethink and limit our time to the "here and now", and how to get rid of the pain we are suffering (*Rejected* 170), a theme Puga reflects on in the diary. For example, in her entry titled "93. Tú deberías hacerme recordatorios, Dolor", Puga must remind herself of the present time, of the "AQUÍ", stating that even though it should be pain who makes her think this way, it is actually *escritura* that forces her to do so (88). However, this confrontation of the present time makes Puga realize that she does not want to continue living with Dolor as the main protagonist of her life. Martz confirms that due to the pervasive nature of many disabilities, learning to move ahead and focus on the future can help to minimize past experiences with the disability and can aid in acceptation and adaptation to the new disabled status (150). Following this idea, in one of Puga's final entries she addresses Dolor and her need to move forward with her life. In this entry she tells him that she must end this cycle and create an ending to the diary (Puga 89). She affirms that while it can stay in her life as an entity with which she must cohabit, she will no longer permit it to be a protagonist in her writing (90). In this sense, she is closing a door of the past, and looking towards a future where she cohabits more harmoniously with Dolor. This can help lead to a transcendence of the body, and a cultivation of acceptance of the suffering that the pain causes (Wendell, *Rejected* 171).

In another instance, Puga speaks to Dolor once again, and tells him that in her new writing "tú resultas obsoleto porque, por un lado, todo va a doler, y por el otro, el dolor va a ser síntoma de curación, no de enfermedad" (91). By doing so, she confirms the new version of herself that accepts her chronically ill body. What Puga is doing here is reframing her subjective experience with rheumatoid arthritis by refusing to write about it any longer. Mintz sustains that female writers who write about their own illness and disability "introduce alternative possibilities into the cultural conversation about embodiment" (7), and at the same time challenge the definition of the normal body. This paradigm shift empowers the disabled or ill woman by validating her corporeal experience (Mintz 7). With Puga's closing action of the book being the disavowal of further perpetuation of Dolor as a protagonist in her autobiographical writing, she takes control of her life and resists self-definition solely based on her illness.

Diario de una pasajera

In *Diario de una pasajera*, Gligo records her battle with cancer, her anxiety caused by her illness, and the psychological counseling sessions that she has with her psychiatrist. During the chronicles of her many treatments, side-effects and doctors' appointments, Gligo, like Sanz and Puga, delves into the topic of writing as a means of healing. At the time of writing this diary, Gligo was an established author with several works published, titled *María Luisa* (1984) and *Mi pobre tercer deseo* (1990). In his work, Couser affirms that, "Before they became ill or impaired, many [disabled people] were already professional writers or worked in professions where writing was part of the job. When such people experience serious illness or disability, it jeopardizes an already valorized individuality; writing, already a valuable professional skill, bids to be an agent of recovery as well as self-expression" (4). Throughout *Diario de una pasajera*, Gligo shows this very notion as an already recognized author as she journals her experiences and exposes the vital importance of writing in her life as an identifying factor. At the same time, much like Sanz and Puga, Gligo uses writing as a way to cope with her terminal illness and the life changes that she now faces.

From the beginning of her diary, in 1992 with the start of her chemotherapy, Gligo reflects on her identity in correlation to writing: "Si no escribo, ¿cómo podré seguir viviendo?...Porque antes escribía desde una herida evidente, propia y profunda, que quizás me limitaba, pero que de alguna manera señalaba el camino. Creo que mis dos libros y el fluir de la vida han sanado en parte esa herida…" (12).[23] Even her academic mentor, Pepe Donoso, tells her that she has to write, though Gligo faces a great difficulty in doing so at the moment, feeling as if she does not have anything clear to say (25). As was aforementioned, Couser clarifies that, with the sudden confrontation of illness or disability in an *autopathography*, the author many times faces an identity crisis and a realization of their own mortality. Similarly, Martz sustains that death anxiety is a common occurrence of the chronically ill or disabled when they realize their mortality (151). Could this be what has happened to Gligo, a disrupted sense of identity by contemplating her own mortality?

Although this notion may appear to ring true on the surface, the reader observes how further along Gligo actually believes the illness has brought her to a heightened sense of identity. For example, after reading the book *La enfermedad como camino* by the psychologist Thorwald Dethelefsen and doctor Rüdiger Dahlke, Gligo states that her terminal illness has united her conscience with her body (39). This aligns with Couser's affirmation about one's experience with illness, stating that "bodily dysfunction tends to heighten consciousness of self and of contingency" (*Recovering* 5). Along the same line, Mintz observes that these *autopathographies* show how impairment or bodily abnormality help to shape a person's identity (212).

As Gligo continues her writing catharsis throughout the diary, the reader witnesses a change in her self-identity with the realizations that she makes during the sessions with her psychiatrist. At one point, she admits that in order to heal herself she

---

[23] The two books she is talking about are *María Luisa* and *Mi pobre tercer deseo*. At this point in her diary she has begun to write a third book about the ghost towns of north Chile, titled *Boca Ancha*.

must write, even though she contemplates if she can ever fully be cured (Gligo 93). She furthers her investigation about cancer in *La enfermedad como camino*, which talks about cancer as an inside contagion, a cell that disobeys the rest of the body (Gligo 136). This definition aligns with the definition by the National Cancer Institute, which states that in all forms of cancer "the body's cells begin to divide without stopping and spread to surrounding tissues" ("What is" n.p.). Gligo even discusses the work of Susan Sontag who, in her book *Illness as Metaphor* (1978), examines the metaphors of illness, such as cancer, in literature. Sontag, like Gligo, fell victim to cancer in 2004.[24]

For Gligo, the writing of her diary is part of her salvation from breast cancer (139), but her text is also intertwined with quotidian events, such as teaching a class of creative writing (149). This is similar to the life-writing of May Sarton who, in her journal *Recovery: A Journal* (1997), discusses her mastectomy and bout with breast cancer. Although her journal does talk about her cancer to some degree, she, like Gligo, writes about other things going on in her life, such as the end of her long-term relationship. Mintz argues that Sarton's journaling technique turns "one's attention to other matters, to the business of getting on with a writing life" (192). In my opinion, this is exactly what Gligo succeeds in doing throughout *Diario* as she, instead of focusing on the deterioration of her body, focuses on the writing of this diary. She mentions that this diary has made her feel more connected to herself as it forces her to "mirarme a mí misma" (Gligo 170), something that adheres to the statement by Couser that writing life-narratives help illuminate the connections between the body and mind (*Recovering* 12).

---

[24] Susan Sontag died from Myelodysplastic syndromes, a type of bone marrow cancer that led to Leukemia (Wasserman n.p.).

In his other work, *Signifying Bodies: Disability in Contemporary Life Writing* (2009), Couser also sustains that corporeal autobiographies help women to assert "control over their own bodies" (4), and that while this control may not shield women from getting cancer, their authorship of life-writing can help them to claim autonomy in their lives.

It is important to note that, like Sanz, Gligo incorporates pieces of fiction that she had previously written into the diary, thus creating a distancing effect for the reader. According to Smith and Watson, this innovative type of writing flows between fiction and autobiography, the same blurred boundary that we saw in *Sange en el ojo* by Lina Meruane explained in Chapter 1. In *Diario de una pasajera*, Gligo shares her diary with her friend and fellow writer, Diamela Eltit who identifies four thematic sections of the text: dreams she writes down, the failed effort of writing her third novel *Boca Ancha*, her reflection on creativity and writing, and the illness (189).[25] Gligo's last entry in her diary reflects, "Y TODO debería ser posible en literatura" (207). What Gligo realizes, I believe, is that despite the deterioration of her physical body, she can use writing as a means of complete self-expression and a manner to live through her writing.

Aging and Corporeal Deterioration: Just a Menopausal Woman's Hysteria?

In the fifth chapter of her book, a chapter titled "A Brief History of Aging," Mintz affirms that older, aging women must deal with stereotyping, such as being physically frail and vulnerable (183), and tend to be ignored in society (185). She also expresses that the "prevalent attitude toward age reads it as a 'catastrophe'", or an "alienating body" (210). Equally, in her work *The Coming of Age* (1970), Simone de Beauvior examines the

---

[25] It is worth mentioning that Diamela Eltit has written on illness as well, and her work "Colonizadas" appears in the anthology *Excesos del cuerpo* by Guerrero and Bouzaglo.

aging person in current society and the suffering that they must endure. As aforementioned, life-writing can be one possible outlet to address this social injustice, and to give a voice for those caught in this aging intersectionality. In *Diario de una pasajera, Diario del dolor,* and *Clavícula,* the female authors must face the fact that they are no longer considered young, and at the same time must accept the new state of their bodies.

As previously mentioned in the introduction to this chapter, age/aging is one of the many intersecting social categorizations of women that can profoundly impact their experiences in society, many times in a negative manner. According to Susan McFadden in her essay, "Feminist Scholarship as a Meeting Ground for Age and Disability Studies", aging "presents a challenge to women who proudly affirm their independence while fearing the very real possibility of dependency and disability" (136). In agreement is Wendell, who states that sometimes medical personnel minimize illness and recommend that women "get over it", something she refers to as ageism ("Unhealthy" 21). Similarly, in her book *Figuring Age: Women, Bodies, Generations* (1999), Kathleen Woodward argues that women are subject to what she calls "double-aging" or "multiple aging" in which the older woman is stigmatized at the age of 50, a symbolic date that corresponds many times with menopause, something generally seen as negative (xiii). Woodward states that:

> It is thus not an accident that many women around the age of fifty experience aging, an experience that does not have the same counterpart in men and thus the same psychological, social, and economic consequences for men. By experiencing aging, I am referring primarily to the internalization of our culture's denial of and

> distaste for aging, which is understood in terms of decline, not in terms of growth and change. (xiii)

In other words, the older woman is both doubly marginalized because of her sex and at the same time because of her age. This negative attribution given to older women has contributed to the increase of a blunt binary of young/old, but fails to dialogue about the in-between (Woodward xvii). Many times this perpetuation of the young/old body binary is through the doctors that treat the middle-aged woman who, as previously mentioned, tend to ignore her problems and ascribe them to menopause. This binary of young/old is portrayed throughout all three autopathographies by Sanz, Puga, and Gligo, each in varying degrees and context, but all serving to exhibit the lived-experience of the middle-aged ill woman.

Clavícula

As was mentioned in the first section, Sanz opens the narrative by describing her experience with pain as she is flying over the Atlantic Ocean on her way to Puerto Rico, a pain that starts in her rib underneath her left breast (13). She immediately becomes preoccupied with the pain, and fears that she is dying (27), much like the fear of Gligo and Puga, even though she has not yet seen a doctor. Sanz expresses to her husband: "Gimo: «Me voy a morir y no voy a poder disfrutar de todas las cosas buenas que me están pasando. Me voy a morir y os voy a hacer sufrir a todos. Me voy a morir sin poder disfrutar de mi felicidad. Me voy a morir sin ganas de morirme»" (74). This fear of death produces a hatred in Sanz towards her own body (117), and the desire to figure out what is going on. According to Fine and Asch, this negative perception of body is common in women, and even more so in women with disabilities (23). Interestingly enough, we see a type of survivor guilt in Sanz after she goes to her gynecologist, a friend who had just lost two sisters to cancer (103).[26] While this is a terrible occurrence, this does not mean that Sanz's experience should be minimized, although the internalization of negative self-concept is prevalent amongst disabled women (Fine and Asch 23).

Sanz opens up about her menopausal state as a forty-seven year old woman who has not menstruated for two years (757). She also explains that when her menopause started, they did a blood test that showed she had high cholesterol, or its medical term Dyslipidemia. According to George, "another aspect of the biomedical view is the disease orientation to menopause, with an emphasis on osteoporosis and cardiovascular disease" (78). Therefore, as a menopausal woman, Sanz had a higher chance of getting cardiovascular disease. After being made aware of her Dyslipidemia, she recognizes all of the "prohibiciones que, desde ese momento, marcan mi vida" (1110). She shares that menopause has caused her to feel less beautiful both on the inside and out (143), and no longer has sexual desire (150). This internalization of feeling self-negativity could be caused, according to Woodward, by Western culture's view of distaste of the aging female body, understood only in "terms of decline" (xiii). Instead of accepting the aging of the female body, society promotes youth and the various manners in which we may maintain it, such as makeup and plastic surgery. Furthermore, Sanz blames herself for the pain she is experiencing because she did not have children, believing it to be "un castigo por no haberme perpetuado en la carne de mi carne" (342). According to de Beauvior, it is common for the menopausal woman to look back at her life and realize the

---

[26] Survivor guilt is a phenomenon in which a person has survived when others have not. This can be after many different types of events such as illness, attacks, and other trauma ("Survivor Guilt" n.p.).

“limitations” placed on her body, now “face-to-face with herself” (*Second* 576). This realization by Sanz causes her to self-blame for her now “limited” body, and the malaise she is feeling. At times, the pain that she experiences colonizes her brain without leaving space for anything else (589), but at once she realizes that she is allowed to validate this pain. She states, “pero hoy me rebelo. No soy una hipocondríaca. No estoy deprimida. Tengo un dolor. Una enfermedad. Lo reivindico. Me quejo” (590-93). At this point she understands that she is allowed to feel the way she does, a much-needed step in her journey of self-validation.

However, Sanz’s declaration seems to be overshadowed by the cognitive authority of the medical personnel that try to figure out her ailment. As she receives various names of illnesses by both friends and doctors, such as fibromyalgia (968) or lupus (970), Sanz reflects on illnesses that women seem to suffer from, stating that they are a mysterious mix of psychiatric, muscular, and neurological problems (977-79). She shares that after three months with her pain, various doctors have diagnosed her lung cancer, anxiety, heart disease, nervousness, fungus, and even nothing (300-305). However, the test results are delayed because, according to the doctors, nothing is urgent (305). What the doctors are doing is mitigating the actual lived-experience of Sanz, despite her having dropped down to 45 kilos (1103), and defining it as a psychosomatic illness. [27] De Beauvior touches on psychosomatic illnesses, stating that the majority of gynecologists agree that nine tenths of their patients are “imaginary invalids”, suffering from physiological symptoms that are purely induced from their psychic state (*Second* 331-32). While this

---

[27] Psychosomatic disorders are used to describe a disease that is made worse by mental influences, or mental factors that cause physical symptoms, even if the physical disease does not exist (“Psychosomatic Disorder” n.p.).

may be possible for *some* women, Wendell argues the contrary, indicating that the use of the term psychosomatic illness is used by doctors to reobtain control over their patients when they cannot provide a cure, simply attributing their pain to their minds resisting recovery (*Rejected* 98). We see various examples of this psychosomatic diagnosis throughout Sanz's work, like when one of her lead doctors prescribes her a great amount of Lorazepam to combat her feelings, indicating that what she is feeling is a psychosomatic occurrence.[28] Instead of determining the actual cause of her pain, this psychiatric diagnosis mitigates what Sanz is going through. After being treated with a copious amount of anti-anxiety medication, she even states that this pharmaceutical accessibility makes her lose faith in the medical system (1474-75). Sanz also gives examples of friends who are considered "locas" after seeing several doctors who attribute their maladies to postpartum depression or anxiety (655). In one instance, Sanz talks about the psychosomatic diagnosis of her friend Isabel, who also had been experiencing her own decline of health. Sanz explains that various gynecologists diagnosed her with cysts and benign tumors, and that, despite the continuity of the pain she was experiencing, told her she was confused and that it was just perimenopause (1425). [29] Once again, through the experience of Isabel, we see the occurrence of doctors labeling women's experiences as simple menopausal and psychosomatic hysteria.

Sanz, as well, goes through an invalidating experience with one of her many doctors after describing to him the pain she is feeling between her sternum and throat.

---

[28] Lorazepam is a drug used to treat anxiety which helps to calm the central nervous system ("Lorazepam" n.p.)

[29] Perimenopause is "the time when the ovaries gradually begin to make less estrogen. It usually starts in a woman's 40's, but can start in her 30's or even earlier" ("Perimenopause" n.p.). During this time, there is a significant drop in estrogen causing menopausal-like symptoms ("Perimenopause n.p.).

The doctor then replies to her that this is impossible (761), and Sanz explains: “Me aparto de él. Él da un paso atrás porque tampoco me cree a mí” (766). In Wendell’s experience, many doctors that cannot explain her medical condition just deny it (*Rejected* 122). She argues:

> When a doctor says to a patient who feels terribly ill or has acute pain ‘There’s nothing wrong with you,’ that doctor obliges the patient to choose between discounting her/his own experience and distrusting the knowledge of someone s/he may have trusted and respected for years. If the patient receives the same judgment from many doctors, or from one or more highly regarded specialists, s/he is forced to choose between asserting her/his own subjectively based ability to know her/his own body and discarding her/his belief in the expertise of medical science. (Wendell, *Rejected* 124)

Wendell also delineates that many patients who have physical symptoms unexplainable to doctors, especially women, are told they are making it up, instead receiving a psychiatric diagnosis (*Rejected* 126). As the reader observes, this declaration by Wendell is perfectly exemplified through both Sanz’s and Isabel’s experience with medical professionals.

As we have seen, throughout her narrative Sanz opens up about her lived-experience of pain, the anxiety it produces her, and manner in which she combats this pain and medical diagnosis through autobiographical writing. Sanz battles epistemic invalidation by doctors by also giving a voice to her friends and their similar sexist medical experiences. According to Smith and Watson, life-writing can be used as a technique to criticize this gendered dehumanizing treatment of medical institutions (146-

47). In this sense, not only does Sanz's writing validate her own subjective experience with illness, but it also opens up a critical dialogue on medical personnel associating women's pain as just a psychological problem, and serves as a "pragmatic/cathartic function" (Quayson 25) for both the reader and audience.

Diario del dolor

Equally, Puga's collection of diary entries is riddled with the pain that she experiences from rheumatoid arthritis, and as mentioned in the previous section, portrays Dolor as a main protagonist in her life. Her bodily deterioration caused by the illness that she now suffers leaves her with a pain that produces "desazón, incomodidad, posturas imposibles" (9) and a body that is in a constant battle. She states that since it has appeared in her life, she can never be alone, and that the pain can appear in her neck, knees, forearms, and waist (9). Puga recognizes that she needs to adapt to her illness, but believes that she will never be able to grow accustomed to it (10) because she has discovered its insidious nature (11). However, Puga takes steps in helping herself, as she uses a cane and is learning to cohabitate with Dolor, "doler/aguantar" (13), even though the reader will witness societal barriers that she must face. Unfortunately, many times society places expectations on aging people that diminish their experience with pain. According to Barbara Levy Simon in her essay "Never-Married Old Women and Disability: A Majority Experience," "Disability, then, is a given both physiologically and culturally, an unavoidable rite of passage, like retirement, for men and women who live past middle age" (218). Must aging people just accept that this is part of life and just get over it? [30]

What perpetuates this thinking is the medical paradigm under which most doctors operate, focusing on the objectification of the body in efforts to find the ultimate cure. This *cognitive authority*, a term seen in Chapter 1 that is used to describe the power that doctors have to validate all patients' medical experiences, oftentimes diminishes or ignores the lived experience that is actually taking place. Couser confirms that many patients feel anger, or express that their treatment was depersonalized (*Recovering* 10). At the same time, patients may experience confusion as the doctors speak to them in "codes and conventions generally unavailable to the patient (Couser, *Recovering* 10). In her diary, Puga tells of the experience that she had with medical doctors upon the diagnosis of her illness, and unlike Gligo, had various negative experiences. She narrates that, "El doctor sigue hablando y yo dejo que sus palabras me rocen como una brisa suave, sin seguirlas porque aunque me gusta su entonación no entiendo nada…" (28). Unable to understand the medical lingo that the doctor is using, Puga finds herself lost and confused about her current situation.

In Wendell's opinion, scientific medicine places too much focus on finding a cure, many times neglecting the quality of the lived-experience of the patient (*Rejected* 94). Puga finds herself in a similar experience when, consulting with an orthopedic surgeon, he tells her not to get an operation (28), stating that, "Ahora tiene la ayuda de la silla de ruedas, pero no está completamente desprovista de movilidad. ¿Por qué no se queda

---

[30] Although aging is inevitable and generally brings other impairment due to illness or the decaying of the body, it must be noted that aging or elderly people have varying levels of impairment/disablement.

así?....Haga usted sus ejercicios, siga yendo a la alberca y adapte su vida. Es lo más que le puedo recomendar" (29). Towards the end of her diaries she shares even more incredulous affirmations made by several doctors, in her entry titled "¿No te he contado, Dolor, lo que me han dicho algunos médicos?" (86). The first doctor told her, "¿para qué operarse? Usted es una escritora, ¿no? ¿Por qué no se compra una cama de hospital? Obliga a la cama a adaptarse a la movilidad de su cuerpo y sigue escribiendo. Dormirá mejor. Cierto, va a quedar un poco contrahecha, pero lo que usted hace es escribir, ¿no?" (86). This statement, both highly offensive and belittling, captures the stoic speech that doctors in possession of cognitive authority sometimes employ. It also exhibits a lack of empathy, something that Couser says is counterproductive and alienates the patient from the doctor (*Recovering* 19). Additionally, Puga gives another example of this depersonalized medical language, as a different doctor asks her with repulsion or pity why she wants to walk, stating that she will not be able to walk very well (87). The same doctor then compares his pink palm to Puga's lack of circulation, and she writes that her self-esteem plummeted in that instant (87). This scenario exemplifies the notion of medical discourse and "its tendency to infantilize patients, reify illness, and medicalize experience" (Couser, *Recovering* 21), ignoring the lived-experience of the patient.

The pain that Puga feels is accompanied by a feeling of depression, now that she realizes she is older and no longer living in a young body and dealing with a degenerative illness. For example, in entry 59 titled "La quebradita", Puga admits that she likes to dance, but is now fearful that her "cadera encementada" (60) would break in any moment, hinting to both her rheumatoid arthritis and her advancing age. Not only does this fear prohibit activities that she once enjoyed, but it also isolates her further from society, something that Martz confirms is common with the internalization of social stigmas of disability (140). Puga confesses that the pain she feels reminds her daily that she is no longer young (62), and that her 58 years of living have now become repetitive (66). She blames her rheumatoid arthritis for her down spirits and lack of laughter as it has taken over the joints in her body, although she yearns to still write and travel (67). In her essay "Illness as Metaphor",[31] Sontag describes illness in relation to all of us. She states,

> Illness is the night-side of life, a more onerous citizenship. Everyone who is born holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place. ("Illness" n.p.)

In other words, illness is a part of every person's life, although some "emigrate" to the place of illness to live there permanently (Sontag, "Illness" n.p.).

In the case of Puga, she indeed has emigrated to the place of permanent illness, her body hurts, which in turn causes her fear (72). In her own words, she explains: "tengo miedo, tengo miedo de que me duelas más, tengo miedo de quedar más imposibilitada de lo que estoy, tengo miedo de morirme" (78). Much like Gligo's fear of further disability and death, Puga, too, fears the worsening of her pain and possible death. She, as well, contemplates her own mortality following the trauma that rheumatoid arthritis has caused her, creating a blurred line between healthy and sick, abled and disabled. What can be

---

[31] I previously mentioned the book by Sontag *Illness as Metaphor*. Sontag also has an essay with the same title.

observed here is an "estranging sensitivity to the disabled/abled binary" in which life-writing by women seize "moments of ambivalent ableism to unknown disability and subjectivity" (Simplican 54). In the same manner, de Beauvior explains this estranged feeling, indicating that some women who have come close to death feel a sense of doubling, "the passive object on which the fatality is operating seems necessarily as if it were another" (*Second* 580). In both Puga's and Gligo's diaries, we observe this blurred line between being able-bodied and disabled, crossing lines between illness and health, life and mortality, and facing the ultimate price of chronic and terminal illnesses.

Diario de una pasajera

With the diagnosis of breast cancer, Gligo, throughout her diary, reflects on her corporeal deterioration, the anxieties and depression she has because of it, and her new category as a middle-aged woman with cancer. Right from the beginning of the narrative Gligo discusses her health issues and the negative consequences that come with chemotherapy. In fact, according to Couser, "one of the less well-known potential side-effects of chemotherapy is the early onset of menopause" (*Recovering* 37), an effect that Gligo must deal with. In one entry, she states how she must have an urgent transfusion of red blood cells, which causes her to go to the emergency room. Immediately following, she explains: "Cuando el banco de sangre me dio el alta, me pareció salir de una cárcel" (21). While Gligo appears to be critiquing the medical system by describing the hospital as a jail, her narrative, out of all three being analyzed, is the one that least criticizes the medical discourse of the doctors that treat her. She does, however, detail the psychiatric sessions that she has with Doctor C., her psychiatrist. While Gligo only refers to the doctor by his last initial, a technique used in Simone de Beauvoir's *A Very Easy Death*

(1964) in which she talks about her mother's cancer diagnosis and the stoic behavior of the medical personnel, Gligo has a much more pleasant experience with Doctor C.[32]

In contrast to the medical doctors described in Chapter 1 in *Sangre en el ojo* and *Fruta podrida*, Doctor C. is very patient with Gligo. Instead of using medical discourse that, according to Couser can be counterproductive (*Recovering* 19), Doctor C. empathizes with the ill woman. For example, Gligo experiences a horrifying occurrence when, at a reunion for the project "Letras de España", at first, nobody recognizes her. This gives her the sensation of non-existence (Gligo 58). In her entry she comments:

> La ausencia del pelo es la cara visible de la mutilación. Según el gigante, la mutilación fue un golpe mucho más fuerte de lo que he aceptado conscientemente. La sensualidad del cuerpo se me hizo ajena y estoy excluida de la naturalidad de lo cotidiano. Tiene razón. No sólo me avergüenza mostrarme desnuda frente a Lucho, sino que es muy duro y difícil elegir ropa, sobre todo en verano: sin escotes grandes, sin cinturas marcadas, con mangas que oculten el brazo derecho a menudo inflamado por la falta de ganglios. (58)

This truthful yet difficult realization is one that many women being treated for breast cancer must face. Garland-Thomson attests that life-writing by ill/disabled women shows that adjusting to the impairment may not be as trying as getting used to the stigmatization and social status that comes with having a disability ("Feminist" 1567). At the same time, Couser explains that in the life-narratives of women going through this type of cancer,

---

[32] *A Very Easy Death* also discusses the effects of cancer as a terminal illness, and shows how many times it results in death. In the case of Beauvior's mother, she was diagnosed with cancer and died six weeks later. In contrast to the books discussed in this chapter, Beauvior is the narrator on the outside, not the owner of the failing body.

showing scenes of buying wigs from chemotherapy-induced baldness and reconstructive surgery after having gone a mastectomy are common themes (*Recovering* 42). Indeed, Gligo begins to contemplate reconstructive surgery following her experience at "Letras de España" and her confession about the lack of intimacy in her relationship due to her bodily shame. This lack of intimacy can lead to a feeling of desexualization, something that Smith and Watson say many women living with cancer must face (142). They confirm that writing about cancer and the desexualization of the "modified female body" is a common theme in the autobiographies of women living with the illness (Smith and Watson 142).

At one point, Doctor C. even goes as far as to tell Gligo that getting reconstructive surgery would be "otro gesto de lucha por la vida" (Gligo 59). Although when analyzed from a feminist perspective one may argue that reconstructive surgery adheres to patriarchal culture's fetishism of breasts, the intact female form (Couser, *Recovering* 43), one must also keep in mind that this experience is not our own. In *Recovering*, Couser lists a few works that reject the use of cosmetic surgery to reconstruct the breast or breasts, such as Deborah Kahane's *No Less a Woman: Ten Women Shatter the Myths About Breast Cancer* (1990), and Audre Lorde's *The Cancer Journal* (1980). Equally, Garland-Thomson condemns reconstructive surgery as it implements the ideals of the normative social structure ("Integrating 23).[33] However, if it comes down to the decision of the woman when she feels that her womanhood is destroyed, shouldn't she be the one to determine what is best for her? When it is all said and done, isn't she the one who has to live with her own body? In the case of Gligo, she does decide that the paralyzing effect that her mutilation is

---

[33] Garland-Thomson brings up the notion of the surgically altered "disabled breast" in relation to cultural norms of the aesthetic breast ("Integrating" 25).

causing her is too damaging to her psyche, and decides to go through with reconstructive surgery.

Another theme that stands out in *Diario de una pasajera* is the facing of one's decaying body, the realization of one's own mortality. Gligo must face her own mortality in the reflection of her mother who, when first seeing her daughter's appearance after various sessions of chemotherapy, seemed "molesta de que el tiempo me hubiese atacado también a mí. La agresión de la vejez se duplica al asistir al deterioro de los hijos" (43). However, it is not until the death of her mother shortly thereafter that Gligo really contemplates death, stating that it has situated itself beside her and that she can almost have a conversation with it (87). This realization of mortality is common in breast cancer autobiographical narratives, such as in Juliet Wittman's *Breast Cancer Journal: A Century of Petals* (1993) and Musa Mayer's *Examining Myself: One Woman's Story of Breast Cancer Treatment and Recovery* (1993) (Couser, *Recovering* 62-68). For Gligo, death was not something that she thought of much, as she confesses that she refuses to give death its own identity (153). Nevertheless, after a scare of the cancer having metastasized into her bones (Gligo 164), she admits her fear of disability and death (180). As aforementioned, Gligo now contemplates her own mortality. She also realizes that having cancer has transformed her from a young woman to a middle-aged "señora". She writes:

> La juventud prolongada por los hijos pequeños y los libros tardíos terminó bruscamente con el cáncer, las operaciones, los tratamientos de radio, hormonoterapia y quimioterapia que no sólo me hicieron tomar conciencia de la vejez y de la muerte, sino que cambiaron bruscamente mi aspecto y la constitución

> íntima de mi organismo, convirtiéndome de un día para otro en una señora respetable. (204)

Gligo is cognizant of this stark change between her youth and her aging body, blaming cancer and its harsh treatments for her sudden decline. Indeed, this realization of aging, according to Wendell, could help bring disability awareness to the non-disabled. She affirms that in the long run, "Realizing that aging is disabling helps non-disabled people to see that people with disabilities are not 'Other,' that they are really themselves at a later time. Unless we die suddenly, we are all disabled eventually" (Wendell, *The Rejected* 18). Not only is Gligo's autobiography a testimony to her lived corporeal experience with cancer as a middle-aged woman, but also a work that illustrates the effectiveness of using life-writing as a cathartic tool to deal with the onset of her terminal illness.

Conclusions

Autobiographical narratives of illness and disability told from the margins of an ableist world can, according to Minz, show how gender and disability intersect in the lived experiences of women (211). Given that disabled women outnumber disabled men (Couser, *Signifying* 184), the chances for sexist medical practice and the engenderment of disability are copious. As seen throughout this chapter, another intersecting factor in women's lives is age, something that generates a broad range of embodiment. However, in this chapter, Marta Sanz, Ágata Gligo, and María Luisa Puga are all middle-age menopausal women who are suffering from chronic and terminal illness, at times being blamed by their menopausal state. As autobiographical narratives of subjective experiences, their embodied stories open up a social discourse about the devastating realization of the female engenderment of illness, propelled by the medical professional that are treating them. We saw the cognitive authority of their doctors, and the belittling of their medical experiences by either attributing their pain to psychosomatic occurrences, or insinuating that, in Wendell's words, "are making it up" (126). This medical belittling by cognitive authorities can lead to both public and private invalidation of the woman's reality (Wendell, *Rejected* 122), and can cause her to embody "the negative discourses about women" (Herndl 10).

However, by the simple act of writing their embodied experiences, these women create a voice for themselves and other women, and validate their own stories of illness and disability. Not only do their narrations create a sense of identity in a body that is ill or disabled by addressing their lived-experiences, they also are used as a cathartic tool by writing oneself out of the patriarchal dominant beliefs of female embodiment (Mintz 22). This writing, or "righting" a disruptive body, term used by Mintz, stimulates a consciousness of the disabled bodied. At the same time, these personal narratives place emphasis on the ordinariness of the ill/disabled woman's experience, and break free from the typical able-bodied/disabled binary that plagues Western society, questioning the notion of normativity.

CHAPTER 4

GENETIC DISORDERS AND MENTAL ILLNESS: LIVING WITH DOWN SYNDROME IN *SI CREES EN MÍ, TE SORPRENDERÉ* BY ANNA VIVES AND MENTAL ILLNESS IN IRENE VILAR'S *THE LADIES GALLERY: A MEMORY OF FAMILY SECRETS*

This third, and final chapter, will be an in-depth juxtaposed study of two forms of illness: one that restricts mental capacity due to a genetic syndrome, and the other a stigmatized cerebral chemical imbalance that surreptitiously attacks the mind and body of its host. In *Si crees en mí, te sorprenderé* Anna Vives is a young girl with Down Syndrome and is aware that she is different yet fights against the stigmas associated with having a (dis)ability. In her autobiographical narrative, Vives, who collaborates with author Francesc Miralles, exposes her experience with a (dis)ability in an ableist society, many times touching on inclusion, assimilation, and the various difficulties she faces. On the other hand, in *The Ladies Gallery: A Memoir of Family Secrets* (2009) by the Puerto Rican author Irene Vilar, the reader becomes aware of the history of mental illness in Vilar's family, including Vilar herself, and observes the diary of a woman who, in various points of her life, attempted suicide. Throughout this diary, the reader also discovers many secrets of Vilar's family, all molding and provoking the mental illness of Vilar.

Although Vilar and Vives have two very different experiences with their disability and/or illness, they both are subject to varying levels of stigma that typically are not associated with physical disabilities. According to Elizabeth Donaldson, the barriers that people with mental illnesses and cognitive disabilities must face are more complex because they, “involve the concept of the self that is the very foundation of our political system” (105). In other words, they are confronted with new challenges due to the psychological nature of the disability in relation to society and the social creation and definition of self. Although their experiences, according to Donaldson, may be more complex, the works of Vilar and Vives both question the notion of cognitive ableism and normalcy, and expose the reality of living with a cognitive and mental disability.

Si crees en mi, te soprenderé

A Brief Synopsis

Si crees is the life narrative of Ana Vives, a young woman from Barcelona who has Down’s Syndrome and who, despite facing obstacles in an able-minded world, succeeds in discovering and utilizing her own abilities. With the help of the writer Francesc Miralles, Vives tells her story of overcoming her difficulties as she exemplifies the disability studies notions of cognitive ableism, stigmas, and support systems, all concepts that will be analyzed in relation to the text further along. Vives, a triplet with two “normal” brothers, opens up the book by talking about her childhood, her medical maladies, and the realization that she is very different from her siblings. Throughout the narrative she explains the various difficulties that she confronts as a person with Down Syndrome, such as problems in school, traversing a new route on her own, or learning to do “simple” tasks such as answering an email or learning to type on a computer.

While Vives candidly talks to the reader about the difficulties of living with Down Syndrome, she chooses to focus on the things that she is capable of doing instead of emphasizing the things that she cannot. After having a bad experience while working at a supermarket, Vives starts to work at Fundación Itinerarium, the place of employment of her brothers Pau and Marc, and her father[34]; it is there where Vives "se siente una luz de fe" (65). After learning basic job functions such as working in a group and typing, Vives begins to feel in her element and creates her own font with the help of those around her.[35] Her family, friends, and even strangers show their support throughout the narrative and encourage Anna in everything that she does. At the Fundación Itinerarium, Vives feels at home, and begins to work on her own typography named *Anna*. She describes the sensation that this accomplishment made her feel:

> Doy las gracias porque, a pesar de haber nacido diferente, puedo hacer cosas que nunca habría imaginado. Doy las gracias a las personas que me acompañan en este viaje, por hacerme ver 'lo que hay' en vez de 'lo que no hay'. Me doy las gracias a mí misma por no haber abandonado. Gracias porque no es fácil aceptarse Down, pero sigo adelante con el apoyo de la gente que confía en mí. (76-7)

By focusing on her capabilities instead of her disabilities, Vives is able to successfully create this font, despite having previous difficulties while working at the supermarket.

Her accomplishments continue as her font is chosen by Jorge Lorenzo, a famous motorist, who wants this font to be used on his new helmet. F.C. Barcelona also uses her font for their uniforms, chosen by player Andrés Iniesta. Further along, she even finds out that she is nominated for Catalana del Año, and makes it into the top ten as a finalist, although she does not end up winning. However, for Vives, it does not matter if she wins

---

[34] The mission of Fundación Itinerarium is to develop projects that help to better social and educational processes (*Fundacion Itinerarium* n.p.).

[35] Currently, on their website, Fundación Itinerarium has a section about Vives, stating, "El objetivo de esta iniciativa es sensibilizar sobre las capacidades de todas las personas. Mostrar como en equipo, con los trazos de letra de Anna, Sumando Capacidades todo es posible" (n.p).

or not; the most important thing is to celebrate that a girl with Down Syndrome is recognized in front of hundreds of thousands of people (151).

Vives even meets the president of the Generalitat who, after telling Ana not to kneel before him, states “No lo hagas, Anna… No tienes que hacerlo. Soy yo quien debe arrodillarse ante ti” (Vives 170). At the end of her narrative, Vives talks directly to the reader and thanks them for having read her story. She encourages the reader to embrace their differences and to write their own story, and explains that, although her life with Down Syndrome has been difficult, she still is a happy person.

Si crees: A Collaborative Autobiography

In her article, “Negotiating the Geographies of Inclusion and Access: Life Writing by Gabriela Brimmer and Ekiwah Adler-Beléndez,” Beth Jörgensen discusses the collaborative autobiography of Gabriela Brimmer, a Mexican poet with cerebral palsy who communicated through pointing to an alphabet board (70). This collaborative autobiography, compiled by Elena Poniatowska and based on letters and interviews with Brimmer and her family, shows the interdependence that some people with disabilities face. Jörgensen states, “The collaborative autobiography narrates a limit-case of how an individual is both enabled and constrained by others in a relationship of interdependence, and is not largely in control of her life course” (70). Unable to fully relay her own life narrative due to her illness, Brimmer must negotiate her human agency due to her physical limitations (Jörgensen 69). This negotiation of human agency and independence in collaboration with Elena Poniatowska demonstrates her acceptance of her bodily and cognitive limitations.

Although collaborative autobiographies can be a means in which the cognitively disabled can tell their own life story, many question the veracity of the information being presented. In their article, “Whose Life Story Is It? Self-Reflexive Life Story Research with People with Intellectual Disabilities,” David Henderson and Christine Bigby discuss the genre of collaborative autobiographies:

> …these autobiographies occupy an awkward position between two more established genres of life writing. On the one hand, we have autobiography, where the narrator, subject, and writer are all the same person. On the other hand, we have biography, where the narrator and writer is one person and the subject is someone else. Between these two poles, and drawing on features of both genres, is collaborative autobiography, in which the writer is one person but the narrator and subject is someone else. (45)

This mix of genres, on one hand, is critiqued as misleading the reader into thinking of them as pure autobiography (Henderson and Bigby 45). Many co-collaborative authors have muted their own voices in order to ascribe all the narrative power to the disabled coauthor (45). Henderson and Bigby provide the example of Dorothy Atkinson and Mabel Cooper in the work *Mabel Cooper’s Life Story* (1997). Atkinson helped Cooper write her life story by tape recording sessions of their conversations and then transcribing and re-writing them using first person into a more chronological order and attributing authorship to Cooper (45-6). Henderson and Bigby explain how in many collaborative narratives, the extent of the role of the non-disabled author is not indicated. They state:

> In their attempts to give voice to the voiceless, life story researchers have silenced themselves—that is, relinquished rather than shared authority—to the detriment of

> the stories they wish to tell. If we mask the processes involved in amplifying the voice of people with intellectual disabilities, then the question could be raised as to whether we, too—the facilitators—are engaging in a more hidden process of disempowering (or misrepresenting) the narrator. That is not to say that any attempt to give voice to individuals with intellectual disabilities, or tell a story from their point of view, is futile. Yet given the vulnerability of the subject in question, the potential for misrepresentation should at least be acknowledged, if not openly confronted on the page.

In other words, while these collaborative life narratives can be a significant resource and platform for the cognitively disabled to express their life stories, Henderson and Bigby believe that it is important for the facilitator to be straightforward about their shared authority in order to mitigate misrepresentation.

Si crees is a similar case; much like the autobiography of Gabriela Brimmer, Vives' narrative is a collaborative autobiography that, although demonstrating Vives' interdependence on her family and Miralles, is able to show her own self-expression through the recollection of her life. However, upon reading the text, one begins to question the level of involvement of Vives in writing this narrative. Francesc Miralles is recognized as a co-author, although in much smaller letters on the cover of the narrative, and very briefly prefaces his involvement in the text. Much like the interviews that Poniatowska did to help compile the life narrative of Brimmer, Miralles explains that he, as well, interviewed Anna and her family about the details and trajectory of her life (Vives 10). However, the extent of his involvement is not clearly explained, and although the text is written in first person from the perspective of Vives, the reader is left wondering if a woman with Down Syndrome could have indeed written a text of 176 pages. It appears that, much like with *Mabel Cooper's Life Story*, Miralles compiled a chronological narrative by interviews with Vives and attributes full authorship to her.

However, in agreement with what Henderson and Bigby affirm, this attribution of full authorship confuses and misleads the reader and causes certain misrepresentation on the level of Vives' true involvement. This misrepresentation, in turn, provokes the reader to question the narrative's veracity. Furthermore, it is worth mentioning that Fundación Itinerarium and Francisc Miralles have the copyright to the autobiography, and not Vives, thus sparking the question of the motive of the text. Was this collaboration indeed the self-expression of Vives' life story, or was it propaganda by part of the Fundación Itinerarium? How much did Anna really contribute to the creation of the text? Is the voice that the reader hears truly that of Vives? Contradictions aside, Vives, along with Miralles, do, at least, bring awareness for and recognition to people living with Down Syndrome through this collaborative narrative, however controversial.

Disabled or Differently-abled?

While the definition of cognitive and physical ableism varies from one society to the next, when a person appears unlike the rest of the able-bodied community, prejudicial and stereotypical images are formed. In their article "Handicapsm", Douglas Biklen and Robert Bogdan affirm that, "handicapped people are treated in ways that correspond to their stereotypes and are rewarded for living up to others' image of them… Thus they learn the role of the handicapped and fall victim to the self-fulfilling prophecies" (5). This statement by Biklen and Bogdan creates a negative connotation when it comes to being judged based on corresponding stereotypes. However, what were to happen if, instead of focusing on what the (dis)abled person cannot do, one focuses on what the (dis)abled person *can* do? In his article “Constructing Normalcy”, Lennard Davis explains that “the problem is the way *normalcy* is constructed to create the “problem” of the disabled person” (3). In other words, the construction of societal and cultural norms promotes the construction of *normalcy* and rejects any body or mind that does not fall into its definition.

Nevertheless, in *Si crees,* Vives appears to break with this notion of normalcy, and instead of living up to the negative corresponding stereotypes associated with her genetic disorder, she is instead pushed by those around her to break those stereotypes and thrive with her disability.[36] The narrative opens up by her explaining: “El libro que tienes en tus manos es como el cuaderno donde escribo todo lo que pienso, no tiene principio ni fin. En él plasmo lo que me gusta y lo que no, mis deseos y mis problemas, también mi *característica*: el síndrome de Down. Esta es la historia de un sueño: el de vivir como los demás” (Vives 13). Many times throughout the narrative, Vives seems to flow in and out of identifying as disabled, exemplifying the notion by Marja Mogk that, “disability is perhaps our only temporally contingent minority category: anyone can join at any time. The possibility of impairment —or additional impairment— is presumably daily and lifelong for all of us, although we often choose not to recognize it (10). In other words, we all will suffer from some form of impairment or disability in our lifetime, but it is up to us to decide to acknowledge it.

---

[36] The notion of support systems will be elaborated in relation to the familial support that Anna Vives was able to experience in order to help her overcome various challenges.

Right from the beginning of her narrative, Anna Vives opens up a dialogue about the terms “minusválidos” and “discapacitados”, and explains that her brother Marc would always get mad when he heard somebody use those terms because he believes that every person is unique and valuable, and nobody is worth less than somebody else (16). According to Rosalyn Benjamin Darling, using these terms is simply a stigmatization in Western society that views individuals as inferior (16). She states, “Stigmatization is a form of societal reaction to those who are viewed as different because they do not conform to society’s norms regarding appearance or behavior” (16). This societal view of stigmatization is what creates disability, focusing on normalcy and the able-bodied. However, it becomes clear that those around Anna stress the importance of focusing on capabilities and not disabilities, emphasizing what one can do and not what one cannot.

Consequently, it is necessary to mention what will happen if the person with a disability is taught to always focus on what they cannot do instead of what they can. When this occurs, they start to become affected by *learned helplessness*, a psychological condition in which the affected person becomes adjusted to the negative treatment by others and believes that her/his situation cannot change. Fortunately for Anna, and as will be discussed in detail further along, there are many people around her that focus on her abilities, creating learned capability.[37] Nevertheless, she is still aware of some of her differences. In one moment she writes, “De niña yo era muy feliz, hasta que me di cuenta de que era diferente de los demás. Por mucho que mi familia me tratara, en la medida de lo posible, como si no fuera así, supe que habría cosas, como ir a la universidad o tener hijos, que nunca podría hacer” (Vives 34). She continues saying that, for her parents, “no

---

[37] Learned capability is a term that I created.

debía de ser fácil tener una hija con síndrome de Down. Era una época, mediados de los ochenta, en la que las personas con mi *característica* no podíamos vivir del mismo modo que los demás. Nos etiquetaban con palabras feas que creaban en nosotros un efecto Pigmalión negativo" (35). The Pygmalion Effect, according to Josh Kaufman, is when people perform to the levels that others expect of them (n.p.). Therefore, what Vives is explaining, is the negative side to this effect, in which the person lives up to the low expectations that others have of them. This is similar to learned helplessness in the sense that this person will feel defeated and believe they cannot achieve higher goals. It is because of this reason, according to Vives, that one must use positive words such as the capable, and differently-abled, instead of using phrases like "Subnormal", "Mongólico", or "Disminuido" (36). She explains that society should use words that encourage the natural abilities of that person instead of focusing on what they are incapable of doing, therefore creating a positive Pygmalion Effect. In this manner, not only does Vives' narrative reject the construction and utilization of the terms normalcy and cognitive ableism, but it also opens up a discourse on and raises awareness of Down Syndrome and the difficulties that a person living with it might face.

Furthermore, Vives has a psychologist who, since she was little, told her parents that it was necessary to give Vives responsibilities outside of the house, such as going to the supermarket to buy various items. This assignation of tasks promotes autonomy for the person with the disability, focusing on their abilities and encouraging self-growth. Although Vives explains that a simple task such as going to the store can prove to be challenging for someone with Down Syndrome, she later refutes: "he descubierto que al principio las cosas también son difíciles para los que no son Down y tienen dos cromosomas 21" (42). By making this affirmation, Vives demonstrates her likeness to others around her, recognizing that "normal" people also have difficulties that they must face.[38] Nevertheless, Vives must encounter the "normal" people of society and their stereotyping, explaining that when she walks down the street, others look at her in a different way than how they look at her brothers, and she questions if it is because of her Down Syndrome (47). She states: "Cuando voy por la calle y me miran con extrañeza o con compasión, siento que una serpiente de tristeza se enrosca dentro de mí y no me deja respirar. Yo no soy como ellos y, al mismo tiempo, soy como ellos" (21). According to Rosemarie Garland-Thomson in her book *Staring: How We Look* (2009), "Triggered by the sight of someone who seems unlike us, staring can begin an exploratory expedition into ourselves and outward into new worlds" (6), it is, states Garland-Thomson, an act of curiosity that pries into the life of someone else (65). Therefore, staring may provoke anxiety in the person being stared at, and can cause a feeling of shame and anger (Garland-Thomson 68). Furthermore, Beth Jörgensen affirms that people with disabilities many times are subjected to curious and prying gazes that "diminish their value and refuse their humanity" (70). Definitely, Vives becomes aware of the stares of others around her, causing her to become hypersensitive to her disability and questioning her self-worth.

As aforementioned in the synopsis, Vives acquires a job at a local supermarket in order to fully integrate into society, but unfortunately encounters others who do not understand her disability or do not want to take the time to do so. For example, one man who works there tells her to collect baskets and then quickly walks away, leaving Anna

---

[38] I put this word into quotes for lack of a better term; normalcy is a society-created notion.

unsure of what she heard. Vives explains that people with Down Syndrome normally have greater hearing problems than the rest of people, needing things repeated in order to understand. Confirming this issue are Ben Sacks and Amanda Wood in their article, “Hearing Disorders in Children with Down Syndrome”, who quote that, “People with Down Syndrome tend to have a significantly higher incidence of hearing problems than other groups” (n.p.). Unfortunately, like many of those with Down Syndrome and hearing loss, Vives does not comprehend what the supermarket worker had told her, and wanders lost through the aisles of the store (56). This experience was traumatizing for Vives, and after her work contract ends there, she does not go back.

At the same time, her life story stresses the need to focus on the capabilities of a person, perhaps inspiring others to put their disabilities aside and find their niche in society. Furthermore, as has been demonstrated, Vives’ success shows the positive results of the Pygmalion Effect and the opposite of learned helplessness: learned capability. Instead of living up to the stereotypes of a person with a genetic disorder, Vives demonstrates that every person has their own capabilities.

The Support Systems of Anna Vives

Perhaps one of the most under looked aspects of those living with a disability are the support systems that surround them, something that can either positively or negatively affect the life experience of the that person. In their essay, “Support Systems: The Interface Between Individuals and Environments”, Simi Litvak and Alexandra Enders state that, “Medical and rehabilitation professionals, policymakers, and the general public, more than people with disabilities, often do not recognize how important integration and individuation of supports are” (2). This lack of understanding of the importance of support systems by part of medical professionals only creates more barriers for the disabled person. Litvak and Enders continue by saying that, "Supports make it possible for disabled people to carry out their daily lives, gain access to their world, and participate as citizens" (2). Therefore, support systems can play an integral role in reducing the stigmatization of the disabled person by enabling them to participate and function in society. This section is important to the study, as it takes into account family members who witness firsthand the challenges of the disabled, and provide an intricate support system, a key notion in disability studies.

In her narrative, Vives opens up about living with Down Syndrome and the various struggles that she encounters due to her disability. Although she discusses these struggles in detail with the reader, she also places emphasis on the support that she receives daily from both her family and friends, something that plays a big role in the formation of her self-esteem and autonomy. Litvak and Enders explain that an individual's support system serves as an interface between that individual and the multiple variations of her/his environment, and can help shape the individual's role in the community (3). As was mentioned in the previous section, a strong support system can help foster a positive Pygmalion Effect and learned capability, which pushes people to reach higher expectations that others expect of them. As the title suggests, in *Si crees en mí, te sorprenderé,* Vives discusses all the support that she received from those around her, starting with her parents. She states, "Además del regalo de la vida, yo les agradezco a mis padres que me hayan educado en la normalidad, como a cualquiera de mis tres hermanos" (20). Instead of treating Vives like she was completely different, her parents strived to eliminate the boundaries that separated her from her siblings. They never talked to her about her limitations, only about her possibilities. When Anna was young, her parents met an oncologist who explained that she could go as far in life to the extent to which they pushed her (31). According to Abby Wilkerson in her article, "Disability, Sex Radicalism, and Political Agency", people with cognitive disabilities are oftentimes treated as children, when many of them have only mild forms of cognitive impairment (204). This childlike treatment only creates lowered expectations for the person with the disability, thus creating the aforementioned negative Pygmalion Effect. However, this is not true in the case of Vives, even though as she grew older she began to realize that she was unlike her siblings when she started attending a special education school (30). At one point she asks her mother, "¿Hay alguna manera de no tener síndrome de Down? ¿Podré ser algún día como los demás?... El problema es que yo me doy cuenta de que otras chicas de mi edad hacen cosas que yo no hago" (111). On these occasions when Vives insists on her limitations, her parents encourage her by telling her that she is worth just as much as everyone else.

Vives' parents are not the only support system that she has; her brothers Marc and Pau, with whom she works at Fundación Itinerarium, also push her to succeed and do not treat her any differently because of her disability. For example, after she is nominated for Catalana del Año, her brother Marc affirms that even though it may be difficult for some people to accept her candidacy, she will be the representation "de las capacidades", stating that she is going to represent a greater collective (Vives 128). In other words, Vives will be the face of Down Syndrome, and give a voice to others with the same genetic disorder that are unable to advocate for themselves. Further along, Marc states, "No tienes que avergonzarte porque la gente te aprecie y apoye tu candidatura…Piensa que no te están votando solo a ti. A través de tu nominación están apoyando a todas las personas con dificultades y a sus familias. Votan para que estén orgullosos de sus hijos" (Vives 134). Marc recognizes that Anna's candidacy for Catalana del Año is representative of both his sister with a disability and also for all the disabled people in society.

Furthermore, even friends and strangers provide an intricate support system for Vives, encouraging her in her endeavors. At her job with Itinerarium, Anna meets a guy named Julen who does not treat her any differently because she has Down Syndrome. She explains that, "Detrás de mí se sentaba Julen, un chico muy amable. No parecía importarle que tuviera síndrome de Down. Tampoco a Jose, Job, o Roser. Su manera natural de comportarse, ni fría ni demasiado afectuosa, me daba a entender que era normal que yo estuviera allí" (70). This natural integration into the workplace helps Vives to feel no differently than those around her. According to Litvak and Enders, support systems are dynamic and change based on the environment, such as the individual's function at work, which all plays into a "functional ability triangle" (16). They also state that if the environment is "friendlier" for the disabled individual, they will not need as much specialized support, which promotes autonomy and independent living (Litvak and Enders 17). Although Vives references various individuals that support her in her work environment, she mentions Julen multiple times. For example, Julen tells Vives how proud he is of her after she was able to type without making any errors, but even more proud that she did not give up after months and months of trying (73). This workplace support, especially by part of Julen, helps to encourage Anna to be more independent by highlighting her achievements. Additionally, Vives receives support from people that she does not even know, such as students from a class that wrote to her after her font came out. For example, one student wrote, “Impresionado, Anna no tiene una discapacidad. Tiene una plusvalía. Es especial”, and another wrote, “Juntos podemos llegar más lejos que solos. Una persona no es discapacitada, está capacitada para conseguir sus sueños, sobre todo en equipo” (Vives 100). Even strangers are creating a positive environment for Vives, and place emphasis on her capability, not her disability. [39] Not only does this positive reinforcement encourage Vives to continue to contribute in society, but it creates an interpersonal community that produces a “celebration of difference”, attacking the preconceived notion that disability and the deviant mind/body are bad (Kelly 408).

Finally, Vives receives support from the Down Syndrome community, a group that shares the same struggles that she faces. According to Michael Kelly in his article “Disability and Community: A Sociological Approach”, while many times a community responds negatively to an impairment, constructing social identity based on preconceived notions and cultural norms, it is possible for the person with the disability to rise above their impairment presenting “self-identity” to be more than just the disability. He comments, “The disability is not denied as a significant difficulty or as a significant diminution of resources, but the self, which is presented, is more than the disability (403). Because the Down Syndrome community has a cohesiveness between self and disability (in this case Down Syndrome), the sense of Otherness fades away and creates an atmosphere conducive for social acceptance for the person with the disability. This sense

---

[39] In their article, “Disability: An Interactive Person-Environment Social Creation”, Patrick Fougeyrollas and Line Beauregard define *capability* as “a person's potential to accomplish a mental or physical activity” (182).

of community is felt at the time that Anna is chosen as one of the three finalists for Catalana del Año; Vives describes the support she receives:

> Mientras se acercaba el momento en el que serían elegidos los tres finalistas, también mis amigos con síndrome de Down me organizaron un acto para darme ánimos. Me sentí orgullosa mientras coreaban '¡Tú sí que vales, tú sí que vales!'. Yo les dije que lo hacía por ellos, que eran los mejores del mundo. (146)

As a community, her friends with Down Syndrome came together to support one of their own. This, according to Kelly, can prevent a breakdown in intersubjectivity in which the subject feels separate from the world in which they live (403).

As was exemplified above, the support system of Vives is elaborate and fosters a community in which, instead of thwarting her to the margins of an able-bodied society, embraces her differences, focusing on her capabilities. This support from family, friends, and even strangers creates a positive Pygmalion Effect in the life of Vives by believing that she can be part of a productive society. Towards the end of her narrative, Vives recognizes this, stating that one can do anything she puts her mind to, as long as they are surrounded with the right people (165). She quotes, "Esta obra habla de una vida que no ha sido fácil y que, si no fuera por el apoyo de tantas personas, sería todavía más complicada. Tener síndrome de Down es algo duro a lo que me enfrento todos los días, pero aun así consigo ser feliz" (Vives 173).

The Ladies Gallery: A Memory of Family Secrets

A Brief Synopsis

The plot of *The Ladies* is centered on Vilar's stay at various psychiatric hospitals and is interwoven with her familial history to create a fragmented narrative that explains how she ended up in a mental institution. The text representative of her stay at Hutchings Psychiatric Hospital and University Hospital near Syracuse University campus shows her self-exploration of her mental illness and the reasons behind her multiple suicide attempts by cutting, overdose, and gas inhalation. In her efforts to deal with this "journey of madness with seemingly no exit" (Vilar 17), Vilar remembers back to her childhood, her grandmother's attack on Congress, her mother's suicide, and her stay as a psychiatric patient:

> MARCH 1, 1977. On the twenty-third anniversary of the attack on Congress, her daughter commits suicide in Puerto Rico. The mother is flown secretly to the island for a day to attend the funeral. FEBRUARY 1, 1988. A gray winter day: the daughter's daughter becomes a suicide patient at Hutchings Psychiatric Hospital, in Syracuse, New York. (1)

After this description, Vilar goes in between her present-day stay in the psychiatric ward (where she describes her interaction with other patients and doctors, the amount of pills they give her, and the stoic behavior of some of the medical professionals that she encounters), and the story of her family history, starting with her grandmother, Lolita. Throughout the plot, the reader gradually gets bits and pieces of information about Lolita's role as a Puerto Rican nationalist, the suicide of Vilar's mother by jumping out of a moving car, and her own stay as a child in New Hampshire and later Spain, starting as a young girl and developing into a young woman exploring her sexuality.

Throughout the plot, Vilar also explores the question of colonialism in relationship to the philosophy of Puerto Rican nationalism, the country's identity, and the perpetuation of Puerto Rico as a colonized state of the United States, the reason behind Lolita's attack. The author discusses this notion in various places throughout the narrative as she pieces together the story of her family history and her home nation's journey to Independence. Furthermore, the author delves into the notion of the *insanity* of her grandmother, deemed mentally unstable by the United States government after her attack on Congress, a topic that I will further elaborate in the following sections.

Madwomen and Mental Illness

In her autobiographical narrative *The Ladies,* Vilar shares her experience with mental illness and suicide, and how this impairment affects her life both emotionally and physically. In order to open up a new discourse on mental illness and Hispanic Literature, I will analyze *The Ladies* from a feminist disability theory point of view by focusing on the medical treatment of mental illness, the societal stereotypes that are normally attributed, and the disability identity of the protagonist. To get to my final analysis, I will examine the history of mental illness and its female engenderment, pulling from works such as Michel Foucault's *Madness and Civilization: A History of Insanity in the Age of Reason* (1964), Sandra Gilbert and Susan Gubar's *Madwoman in the Attic* (1979), and Showalter's *The Female Malady* (1985). I will also incorporate a discussion on the impact that colonialism had on the author, and will take this into account while applying disability theory.

Arguably one of the most overlooked and stigmatized impairments, mental illness is essential to the academic discourse and literary application of disability theory. Throughout history, mental illness has been seen as "loss of rationality and self-control, weakness, excess emotion, and proof of an animal or a childlike nature", it is seen as a certain form of inferiority (Hewitt 160). At the same time, mental illness has stereotypically been gendered female, associating women with "madness", seen almost ubiquitously in the Victorian era, as is highlighted by Gilbert and Gubar in their book *Madwoman in the Attic* (1978), and Elaine Showalter's *The Female Malady* (1985). This notion of "madness", however, was due to the lack of physical and scientific proof. Nowadays, modern neuroscience such as an MRI or a PET scan can show cerebral variation.[40] In her article "Women and Madness: Teaching Mental Illness as a Disability", Kim Hewitt states that, "Most important, unlike many disabilities, mental illness is seldom physically visible, tangible, or measurable and yet insidiously impairs mental functioning and behavior in ways that are often difficult for a lay person to grasp" (157).

In her article, "Revisiting the Corpus of the Madwoman: Further Notes toward a Feminist Disability Studies Theory of Mental Illness", Elizabeth J. Donaldson states that, "Fictional representations of madness have a way of influencing clinical discourses of mental illness and vice versa" (93), one always affects the other. She later explains that feminism and its analysis of psychology and psychiatry demonstrates the gendering of psychiatric illnesses, affirming that throughout history many women have been

---

[40] When she wrote this autobiography, Irene Vilar, although a Puerto Rican native, was living in the United States while studying. Therefore, in her case, modern neuroscience exams were more readily available.

inappropriately and falsely denominated as a person with a mental illness (Donaldson 94). This aligns with Gubar and Gilbert's *Madwoman* and Showalter's *The Female*, all stressing the female engenderment of psychiatric disorders.

Consequently, mental illness has been seen as a leitmotiv in literature for many centuries, mainly placed in a liminal position in the sociopolitical context of the narrative. According to Laura Kanost in her article about narrative performances of mental illness, "[w]andering, placelessness, and liminality have long been tropes associated with the spatial and rhetorical othering of mental illness, both —paradoxically— as a lack of subjectivity and as an unparalleled form of creativity and subversiveness" (210). Many times this othering and spatial liminality comes during the confinement of the character in a mental hospital, such as will be seen throughout *The Ladies*. Nevertheless, with the surge in life-writing (as seen and discussed in detail in Chapter 2), these works have transformed the typical depiction of mental illness as a metaphor and stresses the subjective experience of the person with the illness, something Kanost confirms is essential in understanding psychiatric illness in Latin America (221).

Psychotic Sirens and Suicide

> "The song of the Sirens is the great paradox that suicides and madmen know. It is the paradox, too, of every book on suicide written by suicides: they make their nests from the skeletons of dead authors" (Vilar 321).

In her life-narrative, Vilar denominates herself, her mother, and her grandmother as the three Sirens, all which form a generational life cycle: the Child, the Nymph, and the Old Lady (11). Throughout her narrative, Vilar connects her suicidal nature and experience with those of the women in her life: "One day the Irene who was eighteen is disgusted with herself and doesn't know why, and the women in her life become You, plural, mirrors. Suicidal women" (35). Each woman, although from differing generations, all come together to mirror one another. According to the Mayo Clinic, mental illness is hereditary and found in certain genes. Thus, mental illness is more prevalent in patients who have blood relatives that also suffer from one (n.p.). Therefore, it comes as no surprise that these three generations of women must face similar demons, although each deals with them in various ways.

The Child

The first character that will be elaborated in this section is Irene Vilar, the author and main subject in the narrative. Right from the beginning of the memoir, Vilar discusses her admission into a psychiatric ward, explaining as she went into the hospital, she was unaware of the reasons for her sadness (6), and feels that the "start of another day is unbearable" (8). One can see her internal suffering as she states: "I thought they were taking me to an operating room, to cure me, to remove death from inside me, to rid me of the ghosts, the ones I imagined I'd eluded by coming to Syracuse" (10). These ghosts, her whole past of loss and abandonment, is something she cannot escape and must face through therapy sessions and pills that cause her to force emotion, including smiles (Vilar 30). This negative side-effect of the pills she is taking is a normal occurrence with psychiatric medications, according to Andrea Nicki in her article "The Abused Mind: Feminist Theory, Psychiatric Disability, and Trauma". Nicki even states that, in fact, psychiatric symptoms can be worsened with the therapy of certain medications (81). The stigmatization of mental health forces Vilar to question, "How does someone come back from a mental hospital?" (31), a question vital to understanding the lived experience of a mentally ill woman. Nicki states that, "Mental illnesses, like physical illnesses, involve difficulties in social adaption that, without proper accommodation, sources of support, and aid, can be seriously disabling" (81), a notion exemplified in the aforementioned question by Vilar.

Although mental illness can be a genetic disease predisposing some people to developing it, there are other factors that can possibly increase one's chances. In her article, Nicki argues that many times mental illness can be caused by childhood trauma (80). While she gives the example of sexual abuse at a young age, there are many forms of trauma that can play into the formation of psychiatric disturbances. In the narrative, the trauma that the young Irene faces is the suicide of her mother, something that can deeply effect the psyche of the adolescent. Said parental-adolescent conflict, according to Ian Cero and Sarah Sifers in their article about Interpersonal-Psychological Theory, can increase the risk for suicidal behavior (988). [41] While in her stay at one of the psychiatric hospitals, Vilar discusses the suicide of her mom and her absence in her life. She explains that Dr. L. forces her to talk about her mom, stating, "It's become easier for me to talk about my mother's tragedy than the disgust that's been taking over my body, the rotten smell that comes from inside me" (Vilar 77). Is Vilar's feeling of self-disgust connected with this suicide of her mother, or does it exist apart from this loss?

It is not until Vilar's release from the mental ward that the reader finds out her diagnosis of severe depression. She explains: "Before releasing me they had me sign

---

[41] Although this notion will be explored as a possibility in *The Ladies Gallery*, this does not mean that the suicidal behavior of both Vilar and Gladys Mirna are directly caused by the trauma they face or their lack of maternal influence. Mental illness can be caused by a mix of genetic, biological, psychological, and environmental factors ("Mental Illness Basics" n.p.).

some papers and gave me copies. On the page with the diagnosis "acute depression," the word "acute" had been scratched out and above it they'd written "severe"" (Vilar 81). According to the Mayo Clinic, severe depression causes disturbances in day-to-day living, and causes extreme fatigue, physical aches and pains, worthlessness, and self-harm ("Depression" n.p.). The Mayo Clinic also delineates possible causes of severe depression, such as brain chemistry, hormones, biological differences, and inherited traits. While all of these are bodily issues, the Mayo Clinic also explains that there are certain risk factors such as the death or loss of a loved one and having blood relatives with a history of depression and suicide (n.p.), a statement congruent to the affirmation made by Cero and Sifers. Unfortunately, Vilar was faced with both of these risk factors: a mother with depression who committed suicide when she was just a child.

In her article, Nicki explores the notion of romanticizing mental illness, and the need to understand that women who commit suicide are not simply tragic, rather they determine that their lives with a mental illness are unbearable (86). As seen in both Chapters 1 and 2 of this dissertation, disability is a term that is perpetuated through social norms, behavior, and stigma. This is no different with people living with a mental illness, and the reader witnesses the ignorant, stoic behavior of one of the nurses that is treating Vilar. For example, in one scene, Vilar is back at the hospital after another suicide attempt, and the nurse that is changing the bandages on her wrists frowns and asks her why she wants to die (96). She then explains:

> He doesn't like the way the bandage looks and redoes it. The stitches close the two wounds, but blood shows. He cleans the stitches with tincture of iodine, lots of iodine, and it pours down my wrists and drips onto the metal of the table. He

> complains about other patients, especially about a young girl, also a student, whose arms are all chopped up with cuts that she's inflicted on herself over the years. "I can't understand it. I can't understand it," he says. As I ask him what he can't understand he looks again at me and repeats the same words, as if talking to some creature that causes him great revulsion. (Vilar 97)

In this example, the reader observes the negative behavior of the medical professional as he treats her with disdain, appearing to judge her for having attempted suicide. According to Nicki, many people who are not living with a mental illness look at those who do, especially women, as irrational, stupid, or *crazy*, oftentimes not believing that they are truly ill (86). She also concludes that, even though to those on the outside suicidal behavior is seen as erratic and irrational, for those "engaging in it, it is a method of self-preservation that substitutes physical pain for unbearable emotional pain and produces a sense of calm" (Nicki 87). This rings true for Vilar, who, regardless of the exact motives behind her suicide attempt, seeks for relief from her "a journey through madness with seemingly no exit" (17).[42]

Another example of this negative association of mental illness comes in a scene in which Vilar is being evaluated by seven doctors for her psychological evaluation. Throughout this observation, Vilar explains that the psychiatrists were "looking at [her] like [she] was a freak" and taking notes (152). What the doctors' cognitive authority[43] is doing here is creating the Other by making Vilar feel as if she were a freak. This

---

[42] Another subtle example of the "craziness" of women is through the character Madame K, a woman in the psychiatric hospital with Vilar. She had been in Auschwitz where they killed her husband, and now, according to the hospital, she was "losing her mind" (Vilar 128).

[43] Term mentioned in both Chapter 1 and Chapter 2 ascribed to the power of medical professionals to validate everyone's cognitive and bodily experience.

Otherness, according to Susan Wendell, is needed by the subject in order for the Other to carry their own burdens, fears, or rejected qualities (74). It is possible that, in the case of Vilar, the psychiatrists treat her as lesser in order to mitigate their own insecurities. Although Vilar indeed has been through this experience, she does get along well with Dr. O., her newest psychiatrist whom she trusts.[44] After Vilar's psychological evaluation with seven doctors, whom she did not name even by last initial, she has a meeting with Dr. O. in which she reveals to Vilar the results of her examination. With a smile, she shares the diagnosis of "acutely psychotic individual" and the prognosis of "could benefit from long-term hospital stay" (Vilar 274). Although these seven psychiatrists agree that Vilar would benefit from a long-term stay, Dr. O. disagrees and states she believes that Vilar only needs to stay six months. This affirmation causes Vilar to take a sigh of relief, as she will be able to leave the asylum after she finishes treatment. According to Michael Foucault in his work *Madness and Civilization* (1964), mental hospitals have typically been used to as a type of institutional control, confining the abnormal away from society. Is this the reason behind the psychological evaluation results of the seven psychiatrists in the case of Vilar? Or do the doctors truly believe that Vilar's mental illness is bad enough for long-term stay?

Towards the end of the narration, Vilar shares the circumstances that led her to her suicide attempt, a loss of optimism towards life, something the Mayo Clinic confirms is a symptom of severe depression (n.p.). Vilar states that this feeling of repugnance towards herself had been since she was a child (303), perhaps after the suicide of her mother when Vilar was only eight years old. After a visit to the university psychologist,

---

[44] Like we saw in Chapter 2, Vilar also limits naming her doctors as Doctor with their last initial.

Vilar decides to kill herself with gas after her previous introspection. She describes this suicide attempt in detail after having turned on the gas:

> Then I used the last sips of the malted milk to wash down the whole bottle of Tylenol and all the other pills. And then I downed a full bottle of Popov vodka. Then I closed my eyes and waited to pass out. At first it's vertigo, the sensation of falling in space. Then comes something like a dream, but it's a different body that's dreaming. I can't manage to get a hold on the body or the dream. I was still awake. Asleep awake on the towel, feeling the trembling in my legs at the mouth of my stomach, where nausea starts. The feeling of vomiting is followed by heat on the palms of my hands and in my arms. Finally sleep comes. I will die far removed from everybody … From whom? I watched it coming. (306)

Although Vilar is not successful in her attempt (she hears a woman talking about a child outside of her door and decides to stop the gas), this account of her suicide attempt is strikingly honest and descriptive, and provides insight into the psychological process of a suicidal woman. As aforementioned in Chapters 1 and 2, writing about experiences of illness or disability (and in this case suicidal behavior) can be used as a tool for those afflicted to tell their story apart from a society that strictly prohibits the disabled body or mind.

When analyzing the life narrative of Vilar, one notices the inner turmoil that she faces as she discusses her family, particularly the clash of voices that she encounters: that of her mother, the suicidal siren, and that of her grandmother, Lolita, the revolutionary madwoman. She explains that she was both her mother's daughter and Lolita's granddaughter, and that those two voices clashed inside of her (Vilar 240). Perhaps this is due to the fact that Lolita never really treated Gladys as her daughter, and even after her death, Lolita refuses to talk about her, simply calling her daughter "Tatita", never her name. In retrospect Vilar ponders: "Going over this and other conversations, I live through it as if it were a work of fiction in which three generations of women are talking to each other from a distance" (256). Although the voices of her mother and grandmother each talk to Vilar's spirit, she explains that they seem more like fiction than reality: she never really got to have a relationship with her mother before her suicide, and her grandmother was incarcerated for her nationalist beliefs. Maybe this is why, towards the end of the narration, Vilar reveals she is pregnant and plans an abortion, although later on she overdoses on a cathartic and has a miscarriage (314), thus preventing that another child be brought into a broken family.

The Nymph

Throughout the narrative, Vilar talks in length about the "nymph" of the three sirens, her mother Gladys Mirna. Although Irene never ended up committing suicide after various failed attempts, Gladys Mirna kills herself one day after the wedding of her son when Irene was only eight years old by throwing herself out of a moving car with her husband driving and Irene in the backseat. Before her suicide, her erratic behavior showed signs of manic depression, perhaps further stimulated, as Cero and Sifers outline, by the lack of maternal stability throughout her childhood. Gladys Mirna only knew her mother by the pictures she was shown, as her mother was already serving a long sentence in prison. Vilar states that:

> As a child, Mama used to think that the beautiful woman she saw in photographs, the woman she would later see in the newspapers, would come to get her

> someday. And she waited for her. In 1948, Lolita returned to Puerto Rico with her second child, a six-year-old boy. She came back a militant. New York had transformed her. (Vilar 115)

For the young, impressionable Gladys Mirna, Lolita was not what she expected, and it would not be until 30 years later when Lolita would return to bury her daughter. Alongside the absence of her maternal figure, Gladys Mirna had a cheating husband who deceived her on multiple occasions. It is possible that the combination of these two things created what Cero and Sifers denominate as thwarted belongingness. In their words, "Thwarted belongingness is characterized by a perceived deficit in reciprocal care relationships and perceived burdensomeness is associated with the misperception that the world would be better off if one were dead" (987). The lack of relationship that Gladys has with Lolita, according to thwarted belongingness, puts her at more of a risk for suicidal behavior. Cero and Sifers confirm that parental support is necessary to protect against suicide attempts, much more so with girls than with boys (991). Therefore, it is possible that this lack of parental support only heightened the chance of suicidal behavior in Gladys Mirna, although it is not directly presented in the text. On the other hand, it is also possible that her husband's consistent unfaithfulness only added to the deficit in her reciprocal care relationships, which in turn can stimulate suicidal behavior. For example, Irene explains, "That first Christmas he got home late and said that the girl with the long hair was just a friend, that's all. But she, who'd seen them embrace in the square, left the house and went off into the woods to lose herself near the pond" (119). Vilar explains that her mother had threatened suicide many times after finding out about her husband's multiple affairs. Gladys Mirna also alludes to her death in the near future, as she looks at

Irene “with the dissolved eyes of someone who’s not there”, and asks her if she will still love her when she is gone (Vilar 133). This type of mentality is typical of people who are manic depressive, surely in one of her depressive lows in which suicidal plans/attempts are prevalent (“Bipolar Disorder” n.p.). Nicki observes that for people with psychiatric illnesses, many times the mind is seen as Other, a disorderly and untrustworthy part of the person (92). This can cause for the mentally ill person to feel as if there is no help or safe places (Nicki 92), and in the case of Gladys Mirna, that the only escape from her mind was suicide.

Furthermore, Vilar alludes to the fact that Gladys Mirna may have suffered from Dissociative Identity Disorder, a mental illness in which a person’s identity is fragmented into various personality states (“Dissociative Identity Disorder” n.p.). Although she never comes out and says that her mother was identified as such, she does reveal that her mother struggled with the various women/roles she took on. For example, Vilar states “I wonder if making up and putting on wigs was a custom of the seventies or simply her way of protecting herself from all the women she carried inside her: the daughter, the wife, the mother, and, toward the end of her life, the Puerto Rican nationalist” (Vilar 138). Through this exclamation, it is possible that Gladys Mirna suffers from multiple personalities, changing wigs as she changes identities. At the same time, it is also plausible that Gladys Mirna had a hard time dealing with the various roles and demands that were expected of her: daughter, wife, mother, and Puerto Rican nationalist. Regardless of her lack of diagnosis, Gladys Mirna’s suicidal behavior persists, and in one moment attempts suicide in the ocean while Vilar is present (147). In her attempts to drown out her feelings of depression and malaise, Gladys Mirna takes many pills, including valium. In retrospect, Vilar wonders how a beautiful, intelligent 36 year-old woman could fade away without anyone noticing (148). In her article, Nicki explains that many times women who suffer from mental illnesses have a hard time overcoming it:

> But just as the state of one's body or one's mind is not under one's complete control, likewise sensitive attunement to a negative body or mind is not always possible, nor can one always respond appropriately. Particularly overburdened and overstressed people, such as women with multiple roles-self-abnegating mother and wife and full-time worker outside the home-may not have the time or the necessary supports that would allow them to pay attention to their bodily and psychological needs and respond accordingly. (93)

These multiple roles that Gladys Mirna has taken on may have left her overburdened, causing her to not be able to take the necessary steps to respond to her psychological needs. This lack of self-care and appropriate medical diagnosis is potentially what led Gladys to her eventual suicide, an occurrence that Vilar is able to recall in great detail. The suicide came after the wedding of her brother Cheito where Vilar's father was dancing with another woman. On their way back from the wedding, Irene knew that something was wrong, as her mother was acting irrationally:

> When I saw her grab the door handle, I tried to look into her eyes, and when I saw them I didn't wait any longer. I grabbed her arm. I dug my fingers into her shoulder to make her know that for nothing in the world would I let her leave. She pushed. When the door opened, a deafening wind came in. I was tugging. No! No! I was tugging in my direction with all my strength, all my body, as if obliging her to choose. Finally, I didn't feel any more resistance and I was left with a piece of

> black lace in my hands, and I hated her. She'd done what she wanted to do. She'd left me. (157)

After her mother jumped, her father stopped the car to grab her off of the road, where she was not moving; she was pronounced dead at the hospital. According to Zlatka Rakovec-Felser in her article, "Domestic Violence and Abuse in Intimate Relationship from Public Health Perspective", the possible side effects of emotional abuse and childhood trauma are depression, anxiety, and suicidal thoughts or tendencies (65). Therefore, the psychological and emotional abuse caused by her cheating husband, even up to the day of her death, could be a viable reason behind Gladys' suicide. At the same time, as aforementioned, her lack of maternal guidance is another possible cause for her untimely suicide; even at her funeral, Lolita is followed by a crowd of people, and "Amidst all that grief and confusion, Lolita never lost sight of the fact that her personal tragedy was a moment in the collective epic" (Vilar 168). In the eyes of Vilar, even at her mother's funeral, Lolita thought more of her collective nationalist duty than that of a grieving mother. That being said, despite the possible outside risk factors of suicide that she faced, Gladys Mirna was a mentally ill woman who, even with medication, was unable to overcome her demons.

The Old Lady

The third, and final siren that will be discussed is The Old Lady, Vilar's grandmother Lolita who ended up locked up in a mental ward. Right from the beginning of the narrative, Vilar talks about her grandmother's act of martyrdom (6), explaining how Lolita stripped herself of all womanhood as she climbed the Capitol steps in New York City and opened fire on the United States House of Representatives. Lolita carried out this attack on March 1st 1954 to support the Puerto Rican Nationalist Party and, according to Vilar, did it for the five-hundred colonialized years of the Americas (90). Vilar describes the attack as her grandmother ascended the steps of the capital:

> Climb those steps, one after another, and another—how many more? Hundreds, a thousand, the whole colonial past of America was there, its cruelties echoing at each step, unchanged, unforgotten: Mexico, Panama, Nicaragua, Cuba, Haiti … and, of course, Puerto Rico, one of Spain's first New World colonies, one of America's last. (87)

After wrapping herself in a Puerto Rican flag, Lolita reached the front of the gallery and began to shoot, screaming, "Freedom for Puerto Rico!" (Vilar 91).

Due to her rebellious nationalist point of view, Lolita, along with the other three Puerto Rican nationalists that aided in the attack, are seen as mentally ill, a common occurrence with social revolutionaries according to Nicki. In her article, Nicki discusses the prevalence of labeling social revolutionaries as crazy and forcibly locking them up in an asylum or mental hospital prison. She continues:

> Perhaps because of the association of mental illness with political fanaticism, the term has come to denote extremity, intense passion, or a lack of accessible meaning. This seems especially true when seen as synonymous with the term "craziness." Like the label "mentally ill," the label "crazy" is also used as a tool to control people who are simply nonconformist and not genuinely mentally ill. (86)

This is indeed the case after Lolita's attack; after being sentenced to 57 years in prison on July 8th, 1954, she spends three years in jail and is later taken to St. Elizabeth's Hospital in which her nine-month stay consisted of everyone trying to convince her "by every means possible" that she was mad. During this time, she persistently had to fight from actually going crazy (Vilar 261). According to Vilar, in the mind of the United States Government:

> The four Puerto Ricans are no more freedom fighters. They are lunatics, according to Governor Luis Muñoz Marín, crazy and savage people. But in Lolita's purse the police will find a letter written in English: "Before God and the world, my blood calls for the independence of Puerto Rico. My life I give for the freedom of my country. This is a cry for victory in our struggle for independence, which for more than half a century has tried to conquer the land that belongs to Puerto Rico. (92)

In her article, Donaldson explores the notion that madness has been used to signify a rebellious woman, and that associating the two can produce undesirable affects such as interchangeably using the terms "madness" and "mental illness" (Donaldson 93). In other words, by denominating the rebellious woman as mentally ill, not only does society create the Other by eliminating the nonconformist, but it also wrongfully defines what mental illnesses are.[45] At the same time, Nirmala Erevelles discusses colonial intersections and how racial difference, mainly nonwhite people, are labeled as degenerate, diseased, with lowered cognitive abilities, and even being labeled as mentally ill (129), as is exemplified by the forceful confinement of Lolita Lebrón in the mental institution.

---

[45] Also institutionalized at St. Elizabeth's Hospital during Lolita's stay there was Ezra Pound, accused of treason for fascist broadcasts in Italy during World War II. He was deemed "mentally incapacitated" and "diagnosed" with paranoia, spending 13 years in St. Elizabeth's (Vilar 261).

However, as aforementioned, Lolita was not always in a mental hospital while incarcerated. During her first three years of incarceration, she writes a series of messages, one titled "Message from God in the Atomic Age" in which she discusses her mystic vision from God in which he tells her to fight to abolish nuclear weapons. This manifesto, which she sent to President Dwight D. Eisenhower, details these messianic messages and the need for the United States to stop using nuclear weapons. However, after being sent to the President, Lolita was sent to St. Elizabeth's mental hospital. Vilar chronicles: "A part of the "Message from God in the Atomic Age" was sent to President Eisenhower of the United States of America. After a few days two women came to get her. When she saw them coming she knew from experience that this visit wouldn't lead to anything good. The last time it had been to shut her up in solitary for two weeks" (259). Due to her rebellious thoughts about the US Government, Lolita is locked up in the psychiatric ward for nine months.

During her incarceration in St. Elizabeth's Hospital, Lolita is treated as a paranoid woman, a diagnosis given to her by the doctors treating her there. For example, at one point Gladys Mirna goes to visit her mother in the hospital when she was 17. During this visit, Lolita reveals to her daughter that the doctors there had been experimenting on her, and that she had to fight insanity (Vilar 262). On one hand, this demonstrates the notion of using mental illness as a means of social control; just as society rejects the physically disabled and insists on controlling the body, it also rejects the psychiatrically disabled and insists on controlling the mind (Nicki 82). Nicki also elaborates by saying that this social control supports the status quo by enforcing continuous oppression of the colonialized body and mind (83). Along the same lines, Donaldson discusses the romanticization of “madness”, stating that it hinders the possibility for “productive rebellion” or true resistance (Donaldson 93). This means that a strong, rebellious woman, as is the case with Lolita Lebrón, is labeled as mad because society wants to both subdue the non-conformity and prevent productive rebellion. This subduing of the non-conforming woman, even more so the non-conforming colonialized woman, is an occurrence that has been happening for hundreds of years, since the colonialization of the Americas. Even when Lolita was young, she experienced the oppression of the colonized state. Vilar explains: “My mother was born in San Juan at the end of the spring of 1940, and it was a repetition of a phenomenon that has fed the mini-tragedies of colonization; the engineer Paco Méndez wouldn’t acknowledge her, though he did condescend to send her an occasional envelope with cash” (69). Lolita Lebrón is left abandoned by the man who impregnated her, only acknowledging his child by giving Lolita an occasional quantity of cash, and never marrying her.

Lolita Lebron’s life was plagued with the multiple negative effects of colonialization, something that triggers her rebellion against the United States and her desire for Puerto Rican independence. Through this rebellion and aggression during the attack of the House of Representatives, Lebrón is labeled as mentally ill due to her social non-conformity. While Lolita did indeed carry out an act of violence against the United States Government, she was acting on the behalf of the five-hundred years of the colonialization of the Americas, which does not make her mentally ill. This false labelling of mental illness perpetuates “cultural concepts of irrationality and sexist norms of mental health” and “marginalize[s] people with mental illnesses in attacking their personhood” (Nicki 81). Nicki also concludes that “In attacking the personhood of those who are simply nonconformist they contribute to the development of mental health problems in such people" (81). In other words, labelling the rebellious thinker as mentally ill only increases the chances of said person to develop some kind of mental illness as was exemplified by Lolita during her stay at the St. Elizabeth's Hospital.

The Multiple I: Diary Writing in a Psychiatric Institution

As was highlighted in the second chapter of this dissertation, diary writing has been used as a cathartic tool to validate the experience of the disabled woman. In chapter two, we talked about diary writing with physical illness and disability; however, this chapter will elaborate on diary writing while suffering from a mental illness, something Vilar does throughout her narrative in bits and pieces. These excerpts are written in italics, and alternate between her experience in the hospital and a narration about her childhood, the suicide of her mother, and her time in various boarding schools in the United States and in Spain. The diary-like excerpts throughout the narrative portray the daily life of Vilar as a psychiatric patient, and highlight both Vilar's introspection into the reason behind her writing, and the pathological and apathetic treatment that she receives from many of the doctors and nurses. This type of writing is beneficial as it places stress on the subjectivity of the disabled mind, something that oftentimes goes unnoticed or is invalidated by the medical professionals that treat them.

During the first entry of Vilar, the reader witnesses the sub-human treatment of those staying at the mental ward. Vilar explains: "*The nurse arrived from the end of the hall and, with a tug, pulled off the blanket, leaving me uncovered. Get up, she said, as if she were talking to an insect, or a corpse. I made an effort and emerged from my* *numbness. I remembered who and where I was*" (8).[46] Vilar also shares how the guards at University Hospital would not look at her, or look at her as transparent or as an idiot (58). Unfortunately, she is not the only person who is treated poorly at the psychiatric hospital. Further along in the narration, Vilar talks about another patient in the ward with her, Ana Mani, who suffers from manic depression.[47] In one scene, the reader is made aware of the poor treatment of Ana Mani when a nurse attempts to give her some pills. Vilar explains: "she doesn't like the pills, she shrieks and resists like a cornered animal, and she tries to get away, but the other woman is too strong; she shoves the pills into her mouth, under her tongue, and she closes it with a firm hand. Ana has lost. She looks around with wild eyes. She looks at us" (203).

This scene is one of many in which Vilar expresses the stoic treatment of the nurses in the ward. This treatment is also what forces Vilar to think about why she is there, and as she sees the psychologists, social workers, psychiatrists and neurologists, she felt as if she was a "spectator" of her own fable (12). This fable is what causes her to write, as she reflects upon the various voices she hears in her head. She states, "And just as those voices eventually become you as you write, you, in turn, to make your story meaningful, become part of those voices, a closing of the circle that is endurable only as you write" (17). For Vilar, writing is an outlet, a canvas on which to project the multiple voices she is hearing. In their book, Smith and Watson confirm that the autobiographical narrative is a complex act because the "teller" of the story becomes both the object of

---

[46] The original text written in Vilar's narrative that refers to her stay in the psychiatric institutions are put in italics to differentiate it from her family history. Therefore I kept the format to maintain the integrity of the text.

[47] Vilar states that Ana Mani got her nickname from the illness she is suffering (manic depression), although it is unclear who created that name for her.

investigation and the observing subject (1). Vilar, by writing about the voices she hears, becomes part of those voices, closing a cycle as both the observer and the object.

Furthermore, Vilar contemplates the technical language of autobiographical narration and delves into the use of the pronouns “I”, “You”, and “She” and their metamorphosis throughout a narration. She explains that Irene is the Irene of now, of the present, according to the conventions of books and novels, but that when writing it doesn’t matter whether an author says “I”, “You”, or “She” (Vilar 36). Vilar’s statement is in agreement with Mieke Bal in her book about narratology in which she explains that it does not matter whether a narrator refers to her or himself directly, as soon as the narration begins there is an inherit “I” (21). However, as Vilar continues discussing the matter, it becomes clear that her writing also symbolizes a form of *testimonio* in which her voice speaks for the collective “I”, a type of autobiography that is common in present-day Latin American literature according to Smith and Watson (134). In the case of Vilar, the collective “I” that her narrative transforms into is suicidal women. She explains: “One day the Irene who was eighteen is disgusted with herself and doesn’t know why, and the women in her life become You, plural, mirrors. Suicidal women. In the book, one Irene dies so that another Irene can live, but sometimes the fascination is catching” (35). In continuation, Vilar discusses various women writers who are “at war with life”, such as Virginia Woolf, Sylvia Plath, Julia de Burgos, Violeta Parra, and later describes her own suicide attempt with razor blades and gas which then caused her to become admitted to the mental hospital where a third Irene emerges: the unfinished patient (36). Although Vilar confirms that it is painful to write about suicide, putting words onto paper brings them alive and closer to her mother (158). This projection of her mother's voice of the past in the present of Vilar's writing is connected to the future. According to Smith and Watson, autobiographical narration motions towards the future, so the past and present of the narrator are "triangulated" with the future tense, as they are "imagined and projected by the narrator" (93). This allows the author to reflect on the past and present, while also gesturing towards the future, and in Vilar's case, a future where her words take on the form of her mother and grandmother, and where "I", "You", and "She" are only matters of language (296). Consequently, towards the end of her narration, Vilar has a realization:

> And so I began to write, bits and pieces and self-figurations, as if by writing "I"—the much despised "I" of Virginia Woolf—a personal history would become a valid, legitimate source of progress and direction. But the bits and pieces of this pronoun became the life stories of my grandmother and my mother all kinds of stories set free to roam like a medieval incubus, impregnating everything it touched in its cruel transmigrations. (320)

Vilar realizes that she is tied to her mother and her grandmother, and that her narration in the first person not only relates her own life story, but also brings to life their memories. This, in turn, serves as a cathartic tool that helps Vilar to release the voices inside and to highlight both the lived subjective experiences of her mother/grandmother and her own.

Conclusions

Throughout this chapter we have seen two very different disability experiences: a woman with a genetic disorder, and another with a psychiatric illness. However, in both cases, the readers witness life-narratives focalized through the actual lived experiences of Vives, with Down Syndrome, and Vilar, with mental illness. This focalization enables readers to enter the invisible spectrum of the disabled mind, forcing them to reflect on preconceived notions about intellectual disability and psychiatric imbalances. By doing so, the reader is able to observe, and even enter, into the world of cognitive and mental impairment, which in turn encourages them to contemplate the social and political complexities of the disabled mind.

At the same time, *Si crees* and *The Ladies* opens up a broader dialogue on the need for inclusion of mental and cognitive impairment in disability studies and its application to Latin America and Spanish literature. In *Si crees,* the reader witnesses the social implications of living with Down Syndrome, such as staring by others, or the various health symptoms that it implies (auditory, slowed learning) exemplified by the lived-experiences of Vives. However, at the same time, the reader is able to see the full integration of Vives into Spanish society and the capabilities that a person with Down Syndrome indeed has. Nevertheless, the reader is left wondering about the extent of involvement of Vives in her collaborative narrative. *The Ladies*, on the other hand, allows a key-hole effect: the reader is able to observe the lived-experience of Vilar as she stays at a mental institution and the behavior of the medical professionals that treat her, many times in a condescending manner. The reader is also able to, in various instances, contemplate the reasoning behind the suicide attempts of Vilar and enters her past full of family secrets and multiple voices. In this way, both *The Ladies Gallery: A Memoir of Family Secrets* and *Si crees en mí, te sorprenderé* help to contribute to the recognition and acceptation of cognitive and mental impairments as essential in disability studies.

CHAPTER 5

CONCLUSION

In the May issue of a Spanish newspaper in Sevilla titled *Encuentros ABC Discapacidad*, the following slogan appears on the front cover: “No hay sueño inalcanzable” (There is no unreachable dream). Its contents discuss inclusion, foundations, normalization, and accessibility for people living with disabilities. The goal of the newspaper is to integrate the visibility of disability into the public sphere, presenting its audience with information about people living with disabilities and their rights to equality. To achieve this goal, in a section called “La visibilidad ayuda a normalizar la discapacidad”, they affirm, “La visibilidad de las personas con discapacidad en los medios de comunicación, el tratamiento de las capacidades diferentes y la presencia en los productos audiovisuales son el camino para lograr la normalización total del colectivo” (Ortiz 14). In other words, by integrating people with disabilities into society they reach normalization. David Luna, a media collaborator for the group Aspanri and a man living with Down Syndrome, states that “Es muy importante que las personas con discapacidad salgan en los medios a diario” (Ortiz 17). This newspaper gives people living with disabilities a platform on which to express their opinions and concerns, and increase their visibility in the Spanish society.

In quite a similar manner, Fundación Par in Argentina is a foundation that supports the inclusion of people living with disabilities, and seeks to educate those who do not. Their mission reads: “Promover la inclusión de personas con discapacidad y fortalecer en la sociedad el derecho de igualdad de oportunidades. Enfocamos nuestra acción en la formación e integración laboral competitiva, la inclusión educativa y la promoción de los derechos humanos y ciudadanos de las personas con discapacidad" (fundaciónpar.org n.p). Much like *Encuentros ABC de Discapacidad*, Fundación Par promotes and exhibits artwork by artists with a disability, and aids those with disabilities to help integrate into the work system by offering a program that strives to prepare those individuals with the necessary skills for the workforce. On its website are various short videos that provide information about its mission, and show various programs that incorporate and promote the inclusion of people with disabilities.

Both of these associations represent disability advocacy groups that strive to break barriers and create equality for those living with disabilities. They are intended for society as a whole, focusing on the need for inclusion, the full incorporation of disabled citizens in the public sphere. What stands out in *Encuentros ABC Discapacidad* is their incorporation of opinions and quotes from disabled members of the Spanish society, giving them a voice and a platform in which to advocate for themselves. Both *Encuentros* and Fundación Par attempt to educate the greater public and demonstrate the need for more disability awareness in both Spain and Latin America, showing the strides that disability advocacy appears to be making. Nevertheless, when it comes to disability awareness and its representation in Latin American and Spanish cultural products, we see a grave decrease, even though it is extremely necessary. As Benjamin Fraser puts it, "Ultimately it is not merely that disability is represented, but also how it is represented that matters" (xxii). The need to for quality disability representation in Hispanic cultural products is vital for understanding the sociopolitical connection of living with a disability.

Having a disability, both physically and mentally, is a common occurrence amongst the global population, affecting everyone who lives long enough. However, as aforementioned, there appears to be a clear lack of cultural analysis between disability theory and Hispanic cultural productions. Even more of a gap exists between using disability theory from a feminist perspective to analyze these cultural productions. However, many current feminist disability theorists have explored the use of feminist disability theory to examine these cultural productions and have explained the benefits of its application. According to feminist disability theorist Susannah Mintz, utilizing feminist theory to investigate women's narratives on disability and illness can "fundamentally change the way we think about gender and disability, impairment, disease and aging, as well as about the supposedly normal body that consolidates its borders against the demonized category of disability" (7). By presenting their own viewpoint as an ill or disabled woman, female autobiographers who write disability narratives spark a sociocultural dialogue about disability and its stereotypical assumptions in society.

Life writing about these lived experiences is something that is becoming increasingly popular and beneficial; it serves as both a cathartic outlet for the afflicted person and an acknowledgement in society of the individual and collective experiences of those living with a disability. Even more so, and as has been exemplified in this dissertation, we are able to critically look at this life writing by ill or disabled Hispanic women and examine their narratives from a feminist disability theory point of view. Not only does feminist disability studies focalize and stress the negative consequences of gendering illness as feminine, but it, as Stacey Simplican suggests, "can promote an estranging sensitivity to the disabled/ abled binary, seizing moments of ambivalent ableism to unknown disability and subjectivity" (54). In other words, by analyzing disability life writing through a feminist disability theory lens, we are able to encourage a sensitive recognition of the inequality that disabled women may face. It is a recognition at both an individual and collective level that helps to legitimize these lived-experiences. Rosmarie Garland Thomson explains the importance of using and applying feminist disability theory:

> Just as feminism has expanded the lexicon of what we imagine as womanly, has sought to understand and destigmatize what we call the subject position of woman, so has disability studies examined the identity disabled in the service of integrating people with disabilities more fully into our society. As such, both are insurgencies that are becoming institutionalized, underpinning inquiries outside and inside the academy. A feminist disability theory builds on the strengths of both. (14)

In other words, disability studies from a feminist standpoint can help to see the intersectionality of the disabled female in society, examining her position and identity in a sociocultural context. As has been exemplified, the application of feminist disability theory can help to create a more accurate discourse about the lived-subjective experiences of the disabled woman.

To concisely elaborate, there is a great need for the analysis of literary and cultural texts utilizing disability theory, as it creates an interdisciplinary connection that stresses the many intersections on the human identity. Narratives on illness and disability, as Beth Jörgensen and Susan Antebi so eloquently state, have:

> …an undeniable importance for disability studies, just as disability studies brings necessary new insights to our reading of literary and filmic texts. As individuals and as communities, we create our sense of self and other and our collective identities in large part through our absorption and processing of the stories that come to us through time and those that are continually produced in the present. (13)

Therefore, as we read, we are in the process of creating our own identities, situating ourselves in the larger collective. They also highlight the need for disability studies in literature of Latin America, stressing that representations of illness and disability help to uncover the various phenomena such as racial colonialized violence, otherness, global inequality, and the oppression of the disabled (Antebi and Jörgensen 13). As aforementioned in the Introduction to this dissertation, Antebi and Jörgensen do an excellent job at creating an interdisciplinary dialogue between Latin American Literature and disability studies. That being said, what sets this dissertation apart from *Libre Acceso* is my utilization of feminist disability theory and focusing on the analysis of disability/illness narratives written only by women. This helps to more specifically orient the position of the disabled/ill Latin American woman in society.

Consequently, the same can be said for the need for disability studies to take ground in terms of studying cultural productions from Spain. Although there is some form of representation of people with disabilities in Spain, like Fraser mentions in his *Disability Studies and Spanish Culture: Films, Novels, the Comic and the Public Exhibition*, this representation is not comprehensive, and needs to be more fully integrated into Spanish society. He elaborates:

> Even so, research that foregrounds the representation of disabled characters in Spanish cultural products —as opposed to social studies focused more directly on rights and educational or social institutions, or even medically oriented studies of disability (which may be largely peripheral if not anathema to scholars embracing the 'social model')— is a less-recognized if still growing subfield of Disability Studies taken as a whole. (xxii)

Fraser also highlights that, while there are cultural representations of disability in the Spanish society, there are few published literary works that discuss disability as a theme, and if it is used, is depicted only as a narrative device (159). While Fraser's work indeed is vital to examining the cultural depiction of disability in Spain, he investigates the theme of disability in general, not necessarily from a disabled person's point of view.[48] In the same vein, similar to Antebi and Jörgensen, Fraser does not utilize feminist disability theory, but disability theory as a whole.

Therefore, my dissertation, *Hispanic Narratives of the Ill or Disabled Woman: A Feminist Disability Theory Approach* is a work that stresses the importance of the application of feminist disability studies in literature of Latin America and Spain in order to capture the subjective lived-experiences of those Hispanic women living with a disability. The aim of my dissertation has been to investigate and show the lived-experiences that ill or disabled Hispanic women may face in a primarily patriarchal society. After close analysis of these texts, a pattern of themes arose in the narratives of each woman that reared alarming similarities in sociocultural and political complexities

---

[48] While Fraser's book is not about cultural productions made by those living with disabilities, he does state: "It is my hope that the next book I write on disability and Spanish culture will focus almost entirely on works (films, novels, comics, and more) produced by disabled people themselves" (160).

between disability and society. These narratives on disability and illness seem to respond to the need for social and gender equality, showing the intersectionality of the female experience.

The texts that I chose for this dissertation are comprehensive in their totality; I intended to incorporate many kinds of disability including Type 1 diabetes, diabetic retinopathy and blindness, rheumatoid arthritis, breast cancer, general pain, Down Syndrome, and mental illness. Each illness or disability narrative, in different ways, shows the cultural and sociopolitical landscape of living with a body or mind that does not fit into the normalcy standards of an ableist world. These narratives are also comprehensive in their representation of various Hispanic countries and societies, coming from Chile, Mexico, Spain, and Puerto Rico. While these countries differ in policies, social issues, and cultural aspects, the representation of the ill or disabled body and mind in these narratives suggest a connection between the lived-experiences of the disabled Hispanic female. All narratives mentioned in this dissertation represent the embodiment of corporeal and mental difference and help to shape the way in which disability/illness is seen in Latin America and Spain. At the same time, my intent of this work has been to help put feminist disability studies at the forefront of academic conversation as it intersects with the narratives of ill or disabled Hispanic women.

As previously mentioned, my dissertation has uniquely applied feminist disability theory to focalize on the experiences of the disabled/ill Hispanic female. The main goal of my work has been to closely examine life-writing by female authors who write about their illness and/or disability in their narratives. Life-writing on disability, as was shown, is an essential genre that has helped to shape the way society views the disability experience, and in the case of my dissertation, through the eyes of the disabled/ill Hispanic female. Through the analysis of this life writing and as was demonstrated throughout this dissertation, women with physical and/or mental disabilities face stigmas, stereotypes, medical authority, identity crisis, and other oppositions to their lived subjective experiences as an impaired or disabled woman.

In Chapter 1, we saw the analysis of *Fruta podrida* and *Sangre en el ojo* by the Chilean author Lina Meruane who, in many ways, exposes the struggle of living with Type 1 diabetes. Throughout this chapter, I examined the concept of cognitive medical authority and the stigma of living with this illness. As was seen, *Fruta*, the most fictional narrative analyzed in the dissertation, shows the scarily true negative effects of Type 1 diabetes and the embodiment of living with this illness through various descriptions of Zoila's sugar lows and highs. Nevertheless, at the same time I analyzed the disability identity of the young Zoila who, after years of living with her illness, does not want a cure, contrary to societal norms of mitigating the abnormal body. Through this rejection, we have seen the stark contrast of the cognitive authority of her doctors who, throughout the narrative, only want to cure her illness, despite her rebellious acts against their treatments. Furthermore, Zoila's final acts of terror against the hospital further demonstrate the sociopolitical connection between health and state.

Additionally in Chapter 1, I analyzed Meruane's *Sangre en el ojo* that, according to her, is a mix between her own lived-experience with Type 1 diabetes and with some fictitious elements. Throughout this narrative, the reader is able to observe the difficulty of disability acquisition later on in life, as Lina goes blind following the bursting of blood vessels in her eye. Consequently, I applied the disability theory notion of disability acquisition and identity and analyzed Lina's newly found disability identity as a blind woman, drawing upon feminist disability identity politics. At the same time, I showed the disability theory notion that anyone who lives long enough will face some form of disability. Meruane's experience reminds us that our status as member of the ableist world can change in a matter of seconds, and that our bodies are in a consistent state of decay.

While all of the chosen authors of the studied texts suffer from an illness/disability, these women, in many instances, overcome these struggles in society through the help of various factors. These factors include writing as a cathartic tool, support systems, and perseverance, and are essential in the acceptance and overcoming of the disabled body. Although disability and illness serve as a form of disruption in the lives of those living with it, life-writing can help these women transcend their corporeal maladies. In Chapter 2 of this dissertation, I analyzed the use of life writing as a cathartic tool and as a way to empower the middle-aged disabled/ill Hispanic woman. In this chapter, I examined the narratives *Diario del dolor* (Puga), *Diario de una pasajera* (Gligo), and *Clavícula* (Sanz), and analyzed the cathartic implementation of life writing and how this writing helps each author to take hold of her own identity and share her own, subjective lived-experience. At the same time, I demonstrated how this life writing is vital in the acceptance and coping of the disability or illness, used as a type of therapy to heal the body, as stated by Smith and Watson.

As was seen in *Diario del dolor*, the Mexican author María Luisa Puga shares her daily struggle with the pain that she suffers due to her rheumatoid arthritis and the stoic behavior of doctors who tell her she must learn to accept her new, disabled body.

However, through my analysis, I showed how Puga uses her life writing as a way to free herself from the dominating existence of her pain, literally, by the end of the diary, turning a new page in her life book. By the implementation of journaling, I proved, Puga is able to transform from the passive object experiencing pain, to an active subject who will no longer allow pain to dominate. At the same time, I examined how Puga faced a change in identity due to her chronic illness and pain, comparable to the experience of disability theorist Susan Wendell. This chapter showed that while still a part of her identity, Puga refuses to allow her rheumatoid arthritis be the sole reason of her existence.

Similarly, the Chilean author Ágata Gligio in her *Diaro de una pasajera* also uses writing as a tool to reflect on her battle with breast cancer and her identity as a writer. As was examined in Chapter 2, she shares this experience with various entries that help her to accept her identity as a terminally ill and disabled woman. While Gligo was an established author prior to having written her diary, I showed how this journaling enabled her to reflect on the importance of writing as a cathartic tool. I also analyzed the use of life writing as a way to assert control over one's own body, such as G. Thomas Couser asserts. At the same time, I investigated the topic of aging and corporeal deterioration and how Gligo comes to terms with her aging body and realization of her own mortality. Therefore, as was demonstrated in Chapter 2, Gligo's autobiography is a testimony to her deteriorating body and a representation of a greater collective.

The final work discussed in Chapter 2, *Clavícula*, was from the Spanish author Marta Sanz. In the same manner as *Diario del dolor* and *Diario de una pasajera*, in *Clavícula*, Sanz writes about what hurts her as a way to "poner nombre e imponer un protocolo al caos" (295); she even states that she uses writing as a cathartic tool to purge her experience living with an unknown pain. Throughout this chapter, I analyzed Sanz's experience as a middle-aged woman and the negative treatment that she received from doctors, chalking her pain up to menopause instead of listening to her, a common occurrence in the lives of aging women, according to Woodward. These doctors, much like in the experience of Susan Wendell, "minimized her illness, ignored it, denied it, and urged her to get over it. Overall attributes some of this reaction to ageism, speculating that disability" (Wendell 21). I demonstrated how menopausal, aging women are treated differently than a younger woman, and seem to be judged as merely hysterical. Additionally, I investigated Sanz's use of writing as a means to confirm what is happening to her, producing a reality that Smith and Watson, as mentioned in chapter 2, say validate the author's lived experience. I also showed how Sanz's narrative on illness is used as a type of therapy, and consecrates a feminist social collective, speaking on behalf of all women writers, as Sanz so explains in her narrative.

For the three texts of life writing that were exemplified in Chapter 2, the use of journaling or narration was shown to have a therapeutic benefit, although in varying degrees and manners. This cathartic experience, for Puga, Gligo, and Sanz, was beneficial in their dealing with their disabling experience on both a personal and collective level. At the same time, and as Simplican asserts, "Because ableism and sexism intersect to construct disabled women as asexual, miserable and powerless, life-writing is especially useful because it empowers disabled women to tell their own stories that counter sexual and ableist marginalization" (48). In other words, due to their life writing, their lived-experiences of dealing with a disabling illness are validated, and help others to see the disabled woman as just another equal member in society. This, according to Simplican, can help to minimalize varying types of marginalization.

Not only did we see narratives of women who have physical disabilities, but, as analyzed in Chapter 3, we saw two women who suffered from cognitive impairment and intellectual disability and mental illness, two very pertinent disabilities that are less talked about than their counterparts. Perhaps this is partially due to their invisibility; society does not readily see their cognitive and mental impairments as they do with someone with a corporeal disability. Nevertheless, these types of disabilities are equally important in the discussion and analysis of feminist disability studies. Even though we may not see their disability on the outside, this does not mean that they are not struggling on the inside.

In Chapter 3, I started off by analyzing the collaborative narrative *Si crees en mí, te sorprenderé*, by Anna Vives, a young woman from Barcelona living with Down Syndrome. This collaborative autobiography, with the help of writer Francisc Miralles, advocates for the inclusion of people with Down Syndrome and their integration into the workforce (much like was seen in *Encuentros*), although questions arise about the level of involvement of Vives. I discussed how in *Si crees*, the reader sees her story of the difficulties she faces with an intellectual and cognitive impairment, such as learning at a slower rate or not understanding nuances of the Spanish language. I investigated and showed how Vives goes in and out of identifying as disabled, proving the disability theory notion that disability identity fluctuates and is forever changing, seen in many of the other texts analyzed in this dissertation. Vives recognizes that she is different but chooses to focus on things that she can do instead of things that she cannot. Part of her success, as was discussed in Chapter 3, is due to the extensive support systems that surround her, at home, work, and from strangers. Every type of support system of Vives encourages her to live up to her capabilities, instead of treating her as a child due to her disabilities. This positive reinforcement goes against typical ableist normalcy culture that treats people with cognitive disabilities as "childlike" or "lesser". As was shown, this encourages Vives to live the Pygmalion Effect, helping her to reach her full potential, despite having both physical and cognitive disabilities.

On the other hand, the analysis of *The Ladies Gallery: A Memoir of Family Secrets*, by the Puerto Rican author Irene Vilar, shows the connection between mental illness, familial history, and childhood trauma. Vilar exhibits the pattern of mental illness in her family, with the loss of her mother to suicide when she was a young girl. In this section of Chapter 3, we saw the conditions of living in a mental facility, the treatment by psychiatric doctors of their patients, and the connection of mental illness as a taboo condition.[49] However, Vilar's depiction of her experience provides insight to a seemingly invisible disability whose normative features fall outside of the typical disabled corporeal experience. At the same time, throughout the chapter I explored the connection of mental illness gendered as feminine and the association between female rebellion and psychiatric diagnosis, exemplified in the case of Lolita after her attack on the Congress of the United States. Elizabeth J. Donaldson is in agreement as she so accurately explains: "Psychiatry, feminist critics pointed out, unfairly pathologizes women. Mental illness, according to the anti-psychiatry movement, is a myth. The asylum, Michel Foucault (1988) explained, is primarily a form of institutional control" (92). As I demonstrated, this wrongful

---

[49] As was seen in Chapter 3, even the nurses and doctors who treat Vilar treat her as abnormal.

association of mental illness and rebellion takes away from the actual lived experiences of people truly suffering from psychiatric impairments.

Because there is a great lack of work connecting feminist disability studies and Hispanic cultural productions, I believe that this dissertation opens up a discourse of the lived-experiences of the disabled Hispanic woman writer. Not only have I shown that the representation of disabled women through life narrative serves as a link between society and the social collective, but I have also shown the therapeutic benefit of writing about one’s disability/illness. Other scholars have pointed out the need for interdisciplinary connections between disability studies and Hispanic cultural products, and agree that it is essential in literary studies. In this dissertation, I have taken that a step further; I demonstrate the importance of analyzing literature written by Hispanic females from a feminist disability theory standpoint. By doing so, we can establish a platform of advocacy for the disabled Hispanic female that promotes the telling of their own lived-experiences of disability in both Latin American and Spanish societies. Perhaps then we can begin to understand what it is like to live with a disability as a Hispanic woman.

WORKS CITED

Álvarez-Martín, Elena and Priscila Neves-Silva. "Estudio descriptivo de las características sociodemográficas de la discapacidad en América Latina." *Ciência & saúde coletiva*, vol. 19, no. 12, 2014, pp. 4889-98, Accessed 28 June 2017.

American Diabetes Association. Diabetes Basics, 2017. www.diabetes.org. Accessed 24 June 2017.

Antebi, Susan. *Academics.* Victoria College U. of Toledo, http://www.vic.utoronto.ca/academics/s_antebi.htm. Accessed 06 May 2018.

Antebi, Susan, and Beth Jorgensen. *Libre Acceso: Latin American Literature and Film through Disability Studies*. State University of New York Press, 2017.

Arndt, Katrina, and Matthew Wappet. *Foundations of Disability Studies*. Palgrave Macmillan, 2013.

Asch, Adrienne, and Michelle Fine. *Women with Disabilities Essays in Psychology, Culture, and Politics*. Temple University Press, 1988.

Bal, Mieke. *Narratology: Introduction to the Theory of Narrative.* 3rd ed. Toronto, University of Toronto Press, 1985.

Barnes, Colin and Geoff Mercer. "Disability Culture: Assimilation or Inclusion?" *Handbook of Disability Studies*. Ed. Gary L. Albrecht, Katherine Seelman and Michael Bury. SAGE Publications, Inc., 2001, pp. 515-34. SAGE Knowledge. Accesed 3 May 2018, doi: 10.4135/9781412976251.

Baronet, Anne-Marie. "The Impact of Family Relations on Caregivers' Positive and Negative Appraisal of Their Caretaking Activities." *Family Relations*, vol. 52, no. 2, 2003, pp. 137–142., doi:10.1111/j.1741-3729.2003.00137.x.

"Base estatal de datos de personas con discapacidad." *Instituto de Mayores y Servicios Sociales*,http://www.imserso.es/imserso_01/documentacion/estadisticas/bd_estatal_pcd/index.htm. Accessed 27 May 2018.

Beauvior, Simone de. *The Second Sex*. Translated and edited by H.M. Parshley. Alfred A. Knopf, Inc., 1978.

---. *A Very Easy Death*. Translated by Patrick O'Brian. Pantheon Books, 1965.

Biklen, Douglas and Robert Bogdan. "Handicapism." *Foundations of Disability Studies*. Palgrave Macmillan, 2013, pp. 1-16.

"Bipolar Disorder." *Mayo Clinic*. https://www.mayoclinic.org/diseases-conditions/mental-illness/symptoms-causes/syc-20374968. Accessed 19 April 2018.

Butler, Judith. *Gender Trouble, Feminism and the Subversion of Identity*. Routledge, 1990.

Cero, Ian and Sarah Sifers. "Parenting Behavior and the Interpersonal-Psychological Theory of Suicide: A Mediated Moderation Analysis with Adolescents." *Journal of Affective Disorders*, vol. 150, no. 3, 2013, pp. 987–92.

"Cognitive Dissonance." *Encyclopedia Britannica*. Encyclopedia Britannica, Inc. 2017.

Couser, G. T. *Signifying Bodies: Disability in Contemporary Life Writing*. University of Michigan Press, 2009.

Couser, G. Thomas, and Nancy Mairs. *Recovering Bodies: Illness, Disability, and Life-Writing*. U of Wisconsin P, 1997.

"¿Cuántas personas con discapacidad hay en España?", *Europa Press*, 2017. http://www.europapress.es/epsocial/igualdad/noticia-cuantas-personas-discapacidad-hay-espana-20171202120315.html. Accessed 26 May 2018.

Darling, Rosalyn Benjamin. *Disability and Identity: Negotiating Self in a Changing Society*. 2013

Davis, Lennard J. *The Disability Studies Reader*. 3rd ed. New York; London: Routledge, 2017.

---. "Constructing Normalcy". *The Disability Studies Reader*, edited by Lennard J. Davis. 3rd ed. London: Routledge, 2017, pp. 3-19.

"Depression (Major Depressive Disorder)." *Mayo Clinic*. https://www.mayoclinic.org/diseases-conditions/mental-illness/symptoms-causes/syc-20374968. Accessed 16 April 2018.

"Diabetes Prevalence (% of Population ages 20-79)." www.data.worldbank.org/indicator/SH.STA.DIAB.ZS. Accessed 03 February 2018.

"Dissociative Identity Disorder (Multiple Personality Disorder)". *Psychology Today*. https://www.psychologytoday.com/us/conditions/dissociative-identity-disorder-multiple-personality-disorder. Accessed 19 April 2018.

Donaldson, Elizabeth J. “Revisiting the Corpus of the Madwoman: Further Notes toward a Feminist Disability Studies Theory of Mental Illness.” *Feminist Disability Studies,* edited by Kim Q. Hall, Indiana UP, 2011, pp. 91-113.

“El reto de la diabetes en Chile”. www.novonordisk.cl/content/dam/Chile/AFFILIATE/www-novonordisk-cl/Commons/Documents/Compendio%20de%20Diabetes_Chile_2015_es.pdf. Accessed 01 July 2017.

Erevelles, Nirmala. “The Color of Violence: Reflecting on Gender, Race, and Disability in Wartime.” Hall, pp. 108-30.

Ferguson, Philip M. “Mapping the Family: *Disability Studies and the Exploration of Parental Response to Disability.” Handbook of Disability Studies*. Ed. Gary L. Albrecht, Katherine Seelman, and Michael Bury. SAGE Publications, Inc., 2001, pp. 373-95. *SAGE Knowledge*. Accessed 24 Aug. 2017.

Foucault, Michel. *Madness and Civilization: A History of Insanity in the Age of Reason*. France, 1961.

Fougeyrollas, Patrick and Line Beauregard. “Disability: An Interactive Person-Environment Social Creation.” *Handbook of Disability Studies*. Ed. Gary L. Albrecht, Katherine Seelman, and Michael Bury. SAGE Publications, Inc., 2001, pp. 171-94. SAGE Knowledge. Accessed 4 May 2018, doi: 10.4135/9781412976251.n7.

Fraser, Benjamin. *Disability Studies and Spanish Culture: Films, Novels, the Comic and the Public Exhibition*. Liverpool UP, 2013. JSTOR, www.jstor.org/stable/j.ctt5vjhqm.

Fundación Itinerarium. http://www.fundacioitinerarium.org/?lang=es. Accessed 15 June 2018.

Fundación Par. http://www.fundacionpar.org.ar/artepar. Accessed 16 June 2018.

Garland-Thomson, Rosemarie. “Feminist Disability Studies.” *Signs,* vol. 30, no. 2, 2005, pp. 1557–1587. *JSTOR.*

---. “Integrating Disability, Transforming Feminist Theory.” *Feminist Disability Studies*. Kim Q. Hall, Indiana UP, 2011, pp. 13-47.

George, Sharon. “The Menopause Experience: A Woman’s Perspective.” *JOGNN Clinical Studies*, January/February 2002, pp. 77-85. http://www.jognn.org/article/S0884-2175(15)33945-9/pdf.

Gilbert, Sandra and Susan Gubar. *The Madwoman in the Attic.* Yale UP, 1979.

Gleeson, Brendan. "Lost and Found in Space" in *Foundations of Disability Studies*. Palgrave Macmillan, New York, NY, 2013, pp. 69-82.

Gligo, Ágata. *Diario de una pasajera*. 2nd ed., Alfaguara 1997.

González, Francisco M et al. *Discapacidad en Chile: Pasos hacia un modelo integral del funcionamiento humano.* www.senadis.gob.cl, Accessed 01 July 2017.

Grech, Shaun. *Disability and Poverty in the Global South: Renegotiating Development in Guatemala*. Palgrave Macmillan, 2015.

Guerrero, Javier, and Nathalie Bouzaglo. *Excesos del cuerpo: Ficciones de contagio y enfermedad en América Latina*. Eterna Cadencia, 2011.

Hall, Kim Q, editor. *Feminist Disability Studies*. Indiana Press, 2011.

Henderson, David, and Christine Bigby. "Whose Life Story Is It? Self-Reflexive Life Story Research with People with Intellectual Disabilities." *The Oral History Review,* vol. 44, no. 1, 2017, pp. 39–55.

Hewitt, Kim. "Women and Madness: Teaching Mental Illness as a Disability." *Radical History Review,* no. 94, 2006, pp. 155–69.

"Inter-American Convention of the Elimination of all Forms of Discrimination Against Persons with Disabilities." *Department of International Law, OAS*. http://www.oas.org/juridico/english/treaties/a-65.html. Accessed 06 May 2018.

Jörgensen, Beth E. *Department of Modern Languages and Literatures*. U. of Rochester, http://www.sas.rochester.edu/mlc/people/faculty/jorgensen_beth/index.html. Accessed 06 May 2018.

---. "Negotiating the Geographies of Inclusion and Access: Life Writing by Gabriela Brimmer and Ekiwah Adler-Beléndez." *Libre Acceso: Latin American*

Kanost, Laura. "'En ninguna parte': Narrative Performances of Mental Illness in *El porter* by Reinaldo Arenas and *Corazón de skitalietz* by Antonio José Ponte." *Libre Acceso: Latin American Literature and Film Through Disability Studies*, edited by Susan Antebi and Beth E. Jörgensen, State University of New York Press, 2017, pp. 209-25.

Kaufman, Josh. *The Personal MBA.* https://personalmba.com/pygmalion-effect/. Accessed 26 April 2018.

Kearney, Richard. “Narrating Pain: The Power of Catharsis.” *Paragraph*, vol. 30, no. 1, 2007, pp. 51–66

Keller, Helen. “The World I Live In.” *Organization &Environment*, vol. 15, no. 3, 2002, pp. 285–92.

Kelly, Michael P. “Disability and Community: A Sociological Approach.” *Handbook of Disability Studies*. Gary L. Albrecht, Katherine Seelman, and Michael Bury. SAGE Publications, Inc., 2001, pp. 396-411. SAGE Knowledge. Accessed 4 May 2018, doi: 10.4135/9781412976251.n16.

Kleege, Georgina. *Sight Unseen*. Yale Univ. Press, 1999.

Lacom, Cindy. “Revising the Subject: Disability as “Third Dimension” in *Clear Light of Day* and *You Have Come Back*.” Hall, pp. 159-74.

Lee, Hermione. “Introduction.” *On Being Ill* by Virginia Woolf. Paris Press, 2002, pp. xi-xxiv.

“Lina Meruane: ‘La posición de víctima me parece de muy baja intensidad’ ”. *Revista Ñ*. April 2012. www.clarin.com.

Linton, Simi. *Claiming Disability: Knowledge and Identity*. New York University Press, 2010.

---. “Reassigning Meaning.” *The Disability Studies Reade*r, edited by Lennard J. Davis, London: Routledge, 1997, pp. 225-73.

Litvak, Simi and Alexandra Enders. “Support Systems: *The Interface between Individuals and Environments*.” *Handbook of Disability Studies.* Gary L. Albrecht, Katherine Seelman, and Michael Bury. SAGE Publications, Inc., 2001, pp. 711-33. *SAGE Knowledge*. Accessed 23 Aug. 2017

“Lorazepam.” *WebMD*. https://www.webmd.com/drugs/2/drug-8892-5244/lorazepam-oral/lorazepam-oral/details.

Martz, Erin. “A Philosophical Perspective to Confront Disability Stigmatization and Promote Adaptation to Disability.” *Journal of Loss and Trauma*, vol. 9, no. 2, 2004, pp. 139–58.

McFadden, Susan. “Feminist Scholarship as a Meeting Ground for Age and Disability Studies.” *The Gerontologist*, vol. 41, no. 1, 2001, pp. 133–37.

“Mental Illness.” *Mayo Clinic*. https://www.mayoclinic.org/diseases-conditions/mental-illness/symptoms-causes/syc-20374968. Accessed 26 March 2018.

“Mental Illness Basics.” *MedicineNet.* https://www.medicinenet.com/mental_illness/article.htm. Accessed 01 July 2018.

Meruane, Lina. “Blind Spot”. Translated by Beth Jörgensen. *Libre Acceso: Latin American Literature and Film through Disability Studies*, pp. 29-46.

---. *Fruta podrida*. Fondo de Cultura Económica, 2007.

---. *Sangre en el ojo*. Random House Mondadori, 2012.

---. *Viajes virales: la crisis del contagio global en la escritura del sida*. Fondo de Cultura Económica, 2012.

Mintz, Susannah B. “Invisible Disability: Georgina Kleege’s Sight Unseen.” *Feminist Disability Studies,* edited by Kim Q. Hall, Indiana UP, 2011, pp. 67-89.

---. *Unruly Bodies: Life Writing by Women with Disabilities*. The U of North Carolina P, 2007.

Mitchell, David and Sharon Snyder. “Narrative Prosthesis.” *Feminist Disability Studies,* edited by Kim Q. Hall. Indiana UP, 2011, pp. 274-87.

Mogk, Marja. *Different Bodies: Essays on Disability in Film and Television.* McFarland & Company, 2013.

Monteverde-Verdenelli, Malena, Andrés Peranovich-Celton, and Ana Zepeda-Ortega. “Comparación de la prevalencia de discapacidades basada en autoreportes en países de América Latina.” *Población y salud en Mesoamérica,* vol. 12, no. 1, 2016. Accessed 28 June 2017.

Nicki, Andrea. “The Abused Mind: Feminist Theory, Psychiatric Disability, and Trauma.” *Hypatia,* vol. 16, no. 4, 2001, pp. 80–104.

Ortiz, N. “La visibilidad ayuda a normalizar la discapacidad.” *Encuentros ABC Discapacidad,* 29 May 2018, pp. 14-17.

“Perimenopause.” *WebMD.* https://www.webmd.com/menopause/guide/guide-perimenopause#1.

Price Herndl, Diane. *Invalid Women: Figuring Feminine Illness in American Fiction and Culture, 1840-1940.* U of North Carolina P, 1993.

"Psychosomatic Disorders." *The Center for Treatment of Anxiety and Mood Disorders*. http://centerforanxietydisorders.com/treatment-programs/psychosomatic-disorders/.

Puga, María Luisa. *Diario del dolor*. Alfaguara, 2004.

Quayson, Ato. *Aesthetic Nervousness: Disability and the Crisis of Representation*. Columbia UP, 2007.

Rakovec-Felser, Zlatka. "Domestic Violence and Abuse in Intimate Relationship from Public Health Perspective". *Health psychology research,* vol. 2, no. 3, 2014, pp. 62-67. Accessed 15 Oct 2016.

"Rheumatoid Arthritis." *Mayo Clinic*, https://www.mayoclinic.org/diseases-conditions/rheumatoid-arthritis/symptoms-causes/syc-20353648.

Roser, Max. "Life Expectancy." *Our World in Data*. https://ourworldindata.org/life-expectancy. Accessed 01 July 2018.

Sacks, Ben, and Amanda Wood. "Hearing Disorders in Children with Down Syndrome." *Down Syndrome News and Update*, vol. 3, no. 2, 2013, pp. 38-41. https://library.down-syndrome.org/en-us/news-update/03/2/hearing-disorders-down-syndrome/. Accessed 14 June 2018.

Samuels, Ellen. "Critical Divides: Judith Butler's Body Theory and the Question of Disability." *Feminist Disability Studies.* Hall, Kim Q., editor. Indiana P, 2011, pp. 48-66.

Sanz, Marta. *Clavícula: (Mi clavícula y otros inmensos desajustes)*. Anagrama, 2017.

Sarton, May. *Recovering: A Journal, 1979-1980*. Norton, 1980.

Seibers, Tobin. "Disability, Pain, and the Politics of Minority Identity." *Foundations of Disability Studies,* edited by Matthew Wappett and Katrina Arndt, 2013, pp. 17-28.

Sherry, Mark. "(Post)colonizing Disability." *The Disability Studies Reader*, edited by Lennard J. Davis, 1997, pp. 94-102.

Showalter, Elaine. *The Female Malady.* 1st ed., Pantheon Books, 1985.

Simon, Barbara Levy. "Never-Married Old Women and Disability: A Majority Experience." *Women with Disabilities,* ed. Michelle Fine and Adrienne Asch. Temple UP, 1988, pp. 215-25.

Simplican, Stacy. “Feminist Disability Studies as Methodology: Life-Writing and the Abled/Disabled Binary.” *Feminist Review*, vol. 115, no. 1, 2017, pp. 46–60.

Smith, Sidonie and Julia Watson. *Reading Autobiography: A Guide for Interpreting Life Narratives*. University of Minnesota Press, 2001.

Sontag, Susan. *Illness as Metaphor*. Farrar, Straus and Giroux, 1978.

Spivak, Gayatri Chakravorty. *A Critique of Postcolonial Reason: Toward a History of the Vanishing Present*. Cambridge University Press, 2011.

“Survivor Guilt.” *Good Therapy*. https://www.goodtherapy.org/blog/psychpedia/survivor-guilt.

Szymanski, Charles F. “The Globalization of Disability Rights Law from the Americans with Disabilities Act to the UN Convention on the Rights of Persons with Disabilities.” *Baltic Journal of Law & Politics*, vol. 2, no. 1, 2009, pp. 18-34.

Thomas, Carol. *Female Forms: Experiencing and Understanding Disability*. Open UP, 1999.

Torrell, Margaret Rose. “Plural Singularities: The Disability Community in Life-Writing Texts.” *Journal of Literary & Amp; Cultural Disability Studies*, vol. 5, no. 3, 2011, pp. 321–37.

Vilar, Irene, and Gregory Rabassa. *The Ladies' Gallery: A Memoir of Family Secrets*. Kindle Edition, Other Press, 2009.

Vishwanath, Arun. “Negative Public Perceptions of Juvenile Diabetics: Applying Attribution Theory to Understand the Public's Stigmatizing Views.” *Health Communication*, vol. 29, no. 5, 2014, pp. 516–26.

Vives, Ana. *Si crees en mí, te sorprenderé*. Planeta, 2014.

Wasserman, Steve. “Author Susan Sontag Dies.” *LATimes*, 2004. http://www.latimes.com/local/obituaries/la-122804sontag_lat-story.html

Wendell, Susan. *The Rejected Body: Feminist Philosophical Reflections on the Disabled Body*. Routledge, 1996.

---. “Toward a Feminist Theory of Disability” in *The Disability Studies Reader*. 3rd ed. New York; London: Routledge, 2017, pp. 336-53. Print.

---. “Unhealthy Disabled: Treating Chronic Illnesses as Disabilities.” *Hypatia*, vol. 16, 2001, pp. 17–33. ProQuest, doi:10.1111/j.1527-2001.2001.tb00751.x.

"What is Cancer?" *National Cancer Institute*. Feb. 2015. https://www.cancer.gov/about-cancer/understanding/what-is-cancer.

Wilkerson, Abby. "Disability, Sex Radicalism, and Political Agency." Hall, pp. 193-217.

Woodward, Kathleen M. *Figuring Age: Women, Bodies, Generations*. Indiana UP, 1999.

Woolf, Virginia. *On Being Ill*. Paris P, 2002.

---. *The Diary of Virginia Woolf*. Edited by Anne Olivier Bell. Harcourt Brace Jovanovich, vol. 1, 1977.

BIOGRAPHICAL SKETCH

Ms. April Knupp received a BA in Spanish and Secondary Education from Shippensburg University in Shippensburg, PA, with a Level I Pennsylvania Teaching Certificate in 2009, valid to teach Spanish to students in kindergarten through 12th grade. Immediately after her undergraduate degree, she was hired as a high school Spanish teacher at Central Dauphin School District where she worked from 2009-2010 teaching Spanish I-IV. The following academic year, Ms. Knupp accepted a second teaching position at Northern York County School District in Pennsylvania, collectively teaching Spanish levels I-AP during 2010-2015 and was faculty head of the Spanish club. Concurrently during this time, she obtained her MA in Spanish Language and Literature from Saint Louis University, Madrid campus in Madrid, Spain, where she received Honors upon graduation in 2013. Ms. Knupp also worked towards and received her Pennsylvania State Level II Teaching Certificate in 2013, permanent certificate valid to teach Spanish to students K-12. Currently she is working towards her PhD in Spanish with an emphasis in Contemporary Hispanic literature and feminist disability studies at Arizona State University in Tempe, Arizona. She plans to defend her dissertation titled *Hispanic Narratives of the Ill or Disabled Woman: A Feminist Disability Theory Approach* in July and graduate in August.