

Systemic Fibrosis: An Intersectional Feminist Analysis of Cystic Fibrosis

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...Within my eyes  
the flickering afterimages of a nightmare rain  
a woman wrings her hands  
beneath the weight of agonies remembered  
I wade through summer ghosts  
betrayed by vision  
hers and my own  
becoming dragonfish to survive  
the horrors we are living  
with tortured lungs  
adapting to breathe blood.  
(*After Images*, Lorde, 1997).

## **ABSTRACT**

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*Systemic Fibrosis* is about the social construction of cystic fibrosis (CF) and how the representation of this illness often excludes marginalized voices. To explore this, I draw on intersectional feminist theory to demonstrate the lack of diversity in literature, media, and medical representations of CF, particularly with regards to race, gender, sexuality, disability/illness and class. It begins with an introduction to cystic fibrosis and the prevailing images of this illness. Chapter Two provides a literature review that explores how race is represented in medical research on CF, the sociological depiction of illness, and some examples of feminist interventions around illness and disability. In Chapter Three, I discuss intersectional feminist theory, disability studies, queer theory, critical race theory and disability justice as key frameworks for my study. In Chapters Four and Five, I examine some significant representations of CF and illness through an intersectional feminist lens.

**Date: September 1, 2021**

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## **CHAPTER 1: INTRODUCTION**

Cystic fibrosis has recently become more visible in media and popular culture. The dominant images in media are of CFers (a term frequently used by people with CF to describe themselves) who are white, heteronormative and middle-class (Cystic Fibrosis Canada, 2021). The experiences of people of colour, particularly women and queer people, are invisible (Vincent, 2020). Using an intersectional feminist lens, I seek to draw attention to the need to communicate lived experiences of cystic fibrosis that differ from its current hegemonic narrative. I view this research as an activist piece to help draw attention to the lack of representation around this disease, and the impacts that is having on people's lives.

Cystic fibrosis is a major genetic condition that primarily affects the lungs, digestive tract, pancreas, liver, kidneys, heart, sweat glands and the reproductive system. It has been connected to a dysfunctional gene called the Cystic Fibrosis Transmembrane Regulator (Cystic Fibrosis Foundation, 2021). Any errors in this gene are what fundamentally cause this disease. CF causes the overproduction of mucus, which allows for bacteria, viruses and molds to thrive and can cause dangerous long-term infections within the respiratory tract. This extra production of mucus makes breathing very difficult and leads to scarring of the airways. Over time, lung function can significantly drop and a lung transplant may be the only remaining option for survival. A lung transplant will not cure someone with CF however, because the genetic dysfunction remains and mucus will once more be pervasive within the lungs. Most transplant recipients are given an extra five to ten years of life, as long as there is no rejection and no other complications. In recent years, medicines known as modulators have been helping slow the

progression of this illness. CFTR modulators are specific types of medications that help the dysfunctional CFTR protein work in better capacity. The most common genetic code for this CFTR protein is F508del, and currently a new modulator known as Trikafta is helping around 90% of people with CF. There is also another 10% of the CF population that currently is not able to access this drug due to having rare CF genetic codes. Further, cystic fibrosis in terms of genetics can span through different racial backgrounds, for example, someone can be Black and have a 90% code or someone can be white and have a 10% code and vice versa (Joseph, 2019).

Until the 1950s, very little was known about this condition. A website called “Cystic Fibrosis Medicine” that is geared towards healthcare professionals and CF families, offers a historical context on this illness through an exploration of the slow diagnosis of the condition: “in the forties CF was still a new disease and unknown to most people. Milton Graub, a paediatrician and parent who later became president of the US [United States] CF Foundation, recalls that even in 1950, doctors were slow to diagnose his two year old son as having cystic fibrosis” (Cystic Fibrosis Medicine, n.d). Most people who have CF take numerous medications and supplements because of malnutrition and other health concerns and give hours of their time to airway clearance treatments. It is also a very socially isolating illness. Sometimes people cannot finish high school, degrees, or work full time. Hospitalizations are a normal part of living with cystic fibrosis, taking a great deal of time out of their lives. People with CF are also not allowed to be within six feet of one another as the risk of cross-infection is very high (bioMerieux, 2021)

Much of the public discourse surrounding this illness orbits around white people’s experiences and white perspectives on the condition. In fact, CF is often represented in medical research and in the media as an illness primarily affecting people of white European descent

(Farrell, 2018). However, my review of medical research shows that it also affects people of colour in significant numbers (Stewart & Pepper, 2016). Developing an understanding of how social issues affect people with CF is important, as it can lead to a more nuanced approach to medical, social and mental health treatments. It will also make visible the challenges of navigating through the medical system as a person of colour with CF.

It is clear that existing representations of CF, both in medical research and in popular culture, ignore people with complex positionalities around race, gender, sexuality and class. Cheryl Stewart and Michael S. Pepper argue that there has been a lack in both research and adequate diagnosis of African and African diaspora patients with this illness:

CF was first reported in Africa in a black South African baby who died within half an hour of birth. Several years later, twin black African boys became the first confirmed cases of CF at Baragwanath Hospital in Johannesburg, leading the authors to urge clinicians to consider CF as a possible diagnosis in this ethnic group. This recommendation has not always been heeded, to the detriment of non-Caucasian CF patients. Early diagnosis of CF patients is critical because diagnosis after 6 weeks doubles the risk of development of severe pulmonary disease, which is the leading cause of death among CF patients. (Stewart & Pepper, 2016, p.653)

The authors show that inadequate attention to race and cystic fibrosis is an ongoing problem that is impacting expected life outcomes for anyone who is of Black descent.

This case provides one illustration of why an intersectional take on this illness is paramount to helping save lives. More research is needed to address why there is a lack of diverse stories about CF. Who are the gatekeepers and producers of knowledge about this illness? Who are the doctors, who are the surgeons, who are the politicians, who are the policy makers, who are the researchers and above all, who are the patients and families surviving this condition? Except for some performative tokenistic representations of people of colour that sometimes appear on fundraising materials, CF is mostly represented as an illness of white,



heteronormative and middle-class people. A direct example of this is the annual post-secondary Shinerama fundraising event that rallies first year students to partake in a volunteer campaign where activities are set up that help raise funds for CF care/research. A noticeable token factor is the participation of POC volunteers during shine events, even though it may seem diverse, we must challenge this facade by questioning the following: are any of these POC volunteers given insight from shine staff, into representation and CF? That it is not just a white illness and that they should be allowed to question if the funds they are raising are also going towards non-white folks who have this disease (Shinerama, 2021).

This is evident in the three representations of CF that I discuss in this thesis. The Cystic Fibrosis Canada webpage is an example of a charity site that caters to knowledge around the illness, but more could be done to address larger societal and medical concerns around having this disease, particularly people of colour and others who experience social marginalization and exclusion

The recent film *Five Feet Apart* (2019) tells a story about a romance between two young Cfers. It is groundbreaking as CF has never been the focus of a major motion picture. However, from an intersectional perspective, a main concern that is not brought up in the film is the lack of adequate representation of people with CF. A great example of this is some of the backlash the film received such as medical inaccuracies, a production team that had not been open to criticism from the CF community and even though there was a CFer on set and a retired nurse, there were no people cast who actually had CF or were even present in the writer's room. Just because you finally have representation, doesn't necessarily mean it is the correct one (Refinery29, 2021).

The third example is *Transplanted: My Cystic Fibrosis Double-Lung Transplant Story* (2019), a memoir written by CFer Allison Watson. Watson writes about her experience of

undergoing an end-stage CF double lung transplant. Watson's work is crucial for the CF community as it offers insight into the experience of someone who has CF, and lays out the process of preparing for, experiencing, and recovering from transplantation. But given her own experience and location, Watson can only write about all of this from the perspective of a middle-class, white, straight woman. It is an important story around a single CF issue, but a limited one, and like the CF webpage and *Five Feet Apart* (2019), it contributes to the appearance of the CF community as homogenous and not totally encompassing more diverse representations.

To challenge these kinds of representations, this thesis project will examine how existing accounts of CF and CFers in medical, sociological, media and cultural discourse reflect (or do not reflect) the experiences of people who are marginalized in terms of race, gender, sexuality, and class. My research shows that there is very little representation of CF in medical research, media and popular culture that considers racialized and queer women. Using intersectional feminist theory, I analyze existing CF narratives, focusing in particular on CF Canada, film and on non-fictional writing by people with CF. I analyze three different areas of CF representation: the webpage of CF Canada; the film *Five Feet Apart* (2019); and Allison Watson's memoir *Transplanted* (2019). All three of these mediums help raise attention to CF but they also add to the ongoing narrative of it being an illness of heteronormative, white, middle class people.

### **Locating the researcher**

I am someone who has the terminal condition known as cystic fibrosis. I am also a part of the 10% of the CF population who does not have the predominant F508Del code which, as discussed above, is the most predominant genetic code affecting the CF community, thus making me a minority within a minority. I am also of a mixed racial background, carrying both a white German and Black Arab Tunisian ancestry. I chose this topic due to a noticeable lack of representation within the dominant narrative surrounding this illness. This lack of representation has impacted my lived experiences, particularly around the compounding effects of race, ethnicity, disability, class, gender and sexuality. With my appropriate graduate training in Women and Gender Studies, through courses, a research proposal and ultimately this MA thesis I have gained access to queer studies, critical race theory, disability justice, queer crip and intersectional thinking. These frameworks have given me an opportunity to analyze my lived experiences with a women and gender studies framework to help bring out more of the complexity around this condition. Intersectionality has helped me to better articulate many oppressions that are going unnoticed within the CF community. This project has helped me to unpack a much needed conversation around medicine and race from a patient's perspective on CF.

### **Chapter Breakdown**

Chapter Two is an in-depth exploration through a literature review on medical research on race and CF, particularly looking at Black populations and perceived ideas around race, diagnosis of conditions, and Black pain tolerance. I include some personal stories of people who are Black and those who identify as Trans who have cystic fibrosis, and discuss the ongoing

concern around underrepresentation of minority groups in CF medical trials. . I address the sociological depiction of illness in relation to Talcott Parsons's "Sick Role Theory" and how it can impact someone who has a long-term illness/disability. I argue this theory with the help of Audre Lorde through using intersectional thinking. Chapter Three discusses Theory and Method. I begin with the theory of intersectionality in relation to Dr. Kimberlé Crenshaw, Patricia Hill Collins and Sirma Bilge. In order to further deepen intersectional thinking, I turn to Sami Schalk and Alison Kafer who discuss disability, race and sexuality. I explore further with Rosemarie Garland-Thompson, Moya Bailey and Izetta Mobley and Nirmala Erevelles who help me think through critical race theory, disability and feminist theory. I also work with Disability Justice through Leah Lakshmi Piepzna-Samarasinha. In terms of methodology, I am centering marginalized voices and questioning their non-existent representation while taking on an intersectional approach so as to help critique their omission. I draw on methods from three disciplinary areas: Content Analysis (sociology), media analysis (cultural/communication studies), and literary analysis (literature). These questions are framed around a theoretical framework of intersectional feminism/disability justice. These specific questions help me analyze specific representations i.e webpage, film and a written memoir and focus on differing forms of oppressions such as race, class, gender, sexuality and disability/illness. Additionally, it is crucial to consider even just the representation of knowledge around cystic fibrosis, thus the combination of a webpage, cinema and literature helps broaden a wider pedagogical framework around this condition. Chapter Four is a content/media analysis on the CF Canada webpage as well as the film *Five Feet Apart* (2019). To follow is a literature and representation analysis for the *Transplanted* book. In Chapter Five, I explore autoethnography as a method to help share lived experiences. Audre Lorde's *The Cancer Journals* helps to show illness, queerness,

disability and Blackness through self-representation which I explore further through Alicia Griffin's "I AM an Angry Black Woman: Black Feminist Autoethnography, Voice and Resistance." I also draw upon Moya Bailey and Izzetta Mobley's theory of Black Feminist Disability to help broaden an intersectional understanding around race and disability. Poetry as method in relation to Lorde is explored through Bridget Minamore's review of *Your Silence Will Not Protect You*. Lorde's work can be an example of what the CF community needs to better understand intersecting selves in the world of this illness and life experiences around it. Chapter Six concludes with some of the contributions/limitations and future research taking place to help find an end to cystic fibrosis such as emerging research in the field of gene therapy.

## **CHAPTER 2: LITERATURE REVIEW**

In this chapter I discuss some of the findings in medical research on race and cystic fibrosis while drawing on my research question: the invisibility of experiences of people of colour, particularly women and queer people being evident in the CF community. To review traditional sociological views on illness and disability, I discuss Talcot Parsons's "Sick Role" theory, a concept which has been shown to be problematic especially when applied to the terminally ill or permanently disabled. I then argue against this theory by reading it against the work of Audre Lorde who critiques this way of thinking around marginalized bodies. I also introduce some of the feminist theorists I draw from in terms of an intersectional framework.

### **Racialization of Cystic Fibrosis**

Cystic fibrosis is primarily described in medical research as a white person's illness. Schrijver, Pique, Graham, Pearl, Cherry, & Kharrazi (2016) note that this can be problematic for long term survival rates of the condition and that screening for non-white patients is essential. Schrijver and colleagues state the following in regards to the in-adequacy around new-born screening: "in contrast to thoroughly analyzed white CF populations, the CFTR variant spectrum and prevalence in Black, Asian, Native American, and Middle Eastern CF patients have not been elucidated completely. Such knowledge gaps can lead to racial-ethnic disparities in the clinical sensitivity of neonatal screening algorithms and molecular diagnostic testing" (Schrijver et al, 2016, pp. 45-47). Their study directly links the concern around representation and new-born screening.

Black populations are impacted by inadequate diagnostic practices. Stewart and Pepper show that white, European population receives the most medical attention in this regard, as reported: “If the attending physician is unaware that CF is not an ethnically linked disease, this also increases the likelihood that members of the diaspora may be misdiagnosed” (Stewart & Pepper, 2016, p. 4). Training of medical staff to be better informed about the variance in genetic understanding of the illness can fundamentally help save Black populations from an early death from this condition.

A spirometer is a medical device that helps measure how much volume of air is taken in and brought out by the lungs. It usually looks at ventilation which is the movement of air that passes through the airways. A form of racialized medicine is based around spirometry tests, notably how Black populations were tested with this apparatus. In an article called “Science Reflects History as Society Influences Science: Brief History of “race”, race correction”, and the Spirometer,” authors, Lujan and Dicarolo discuss the importance of critiquing the practice of “race correction” in terms of pulmonary testing: “Race correction” is built into the software of spirometers. However, scientists are not trained in history, and the belief that black and white people have innate differences in pulmonary functions has a long and disturbing past” (Lujan & Dicarolo, 2018, p. 163). This practice has roots from Thomas Jefferson’s time; his friend, physician, plantation owner and slave holder Samuel Cartwright, imposed this racial practice on slaves. In relation to Black folks and their “supposed” lower lung capacities, Lujan and Dicarolo report: “Cartwright argued that slavery was beneficial for Black people. He promoted the idea that, because Black people had lower pulmonary capacity, forced labor was good for them” (Lujan & Dicarolo, 2018, p. 164). This cruel practice has been perpetuated for a very long time, essentially killing off many in the Black community. Additionally, lung function is seen to be

more critically considered as there are other factors at play that impact the livelihood of Black folks. The authors observe, “the history of lung function suggests that using race as a biological construct that reflects genetic differences is not based on valid scientific evidence” (Lujan & Dicarlo, 2018, p. 164). Race is a social construct that has far reaching disastrous effects on people’s health, race correction essentially uses race-based biology to proliferate bigotry in medicine. Specifically, “race correction” is a slight adjustment on the apparatus to a 10-15% smaller lung capacity in Black populations compared to white populations.

Another area of misperception in relation to Black populations and medicine is pain tolerance. Ike Swetlitz discusses the misconception of incoming medical staff on how to perceive pain in Black patients vs. white patients:

In a survey of 222 white medical students and residents, about half endorsed false beliefs about biological differences between blacks and whites. And those who did also perceived blacks as feeling less pain than whites, and were more likely to suggest inappropriate medical treatment for black patients, according to the paper published in the Proceedings of the National Academy of Sciences. (Swetlitz, 2016)

Not only is pain not adequately addressed for Black patients but its diagnosis is also poorly understood/administered. This lack of understanding of race and medical care is an area that needs more critical comprehension, Swetlitz adds, “Dr. David Satin, an assistant professor at the University of Minnesota Medical School who directs courses on topics of race, said that this study underscores the importance of teaching medical students to think critically about race and to understand how implicit bias impacts care” (Swetlitz, 2016). It is imperative that medical schools today teach about implicit bias when dealing with anyone of color in relation to giving care. Another professor quoted by Swetlitz agrees: “this particular area is one of the most consequential in medicine”, said Lundy Braun, a professor of medical science in Africana studies at Brown University. “I hope that it helps to settle and change the scandalous undertreatment of



blacks for pain” (Swetlitz, 2016). Knowing that Black folks are not obtaining the pain help they need is distressing to the Black community. This belief has a far ranging effect on differing Black demographics, Swetlitz writes: “a study published last year found that Black children were less likely than whites to receive pain medication in the emergency room while being treated for appendicitis. Two years ago, a study found that black veterans were less likely to be prescribed opioids than were whites for moderate to high levels of pain” (Swetlitz, 2016). These reports are continued examples of racialized medicine and the undo pain that it continues to be placed on the Black community.

When I reflect on the challenges of race and cystic fibrosis, I reach the inevitable conclusion that in our current times, more representation is needed. Lending patient voices to Black experiences around CF is crucial, particularly the area of being misdiagnosed, Teena Mobley is one of those unfortunate patients with CF who has had such an experience, her experience is noted as follows:

Teena Mobley, a black person in the CF community, was originally diagnosed with asthma at a young age. It wasn't until she was ten years old and on the brink of death that she finally received a diagnosis of Cystic Fibrosis. Her doctors didn't consider that she had CF because it is not a predominant disease in the Black community. People often are shocked when she tells them she has CF. (Caroline, 2020)

The urgent need for representation of knowledge within the medical community is what is so important here; to understand and be aware of other non-white groups carrying the genetic make up for this fatal condition and the fatalities that can come from not properly diagnosing people.

Moreover, she states that due to online connections, she has been able to find more folks of colour who share the same terrible disease, Caroline remarks: “she said that continuing to spread awareness is starting to open eyes about the scope of diversity in the CF community. Meeting other people of color in the CF community-virtually, of course, thanks to infection

control protocol-has been exciting. It is an extra connection in addition to having CF” (Caroline, 2020). Due to CF having strict infection protocols around it, going virtual has been a great connecting tool for outreach in the community, particularly if you are one dealing with race and CF.

Kadeem D’Shai Morgan takes us into his life growing up being a Black man and having this genetic condition. Morgan notes, “no one looked like me. Every single person I have come across who had CF was white (Caucasian European); no one was of African heritage” (Morgan, 2020, para. 2 ). Lack of representation of people of colour (POC) impacts young people growing up with this illness. He goes on to explain how growing up he had to hide having CF. He wasn’t able to conceal his skin colour but he did all he could to make CF less visible:

Growing up and living with Cystic Fibrosis was a struggle. My childhood turned me into a pathological liar. I had to lie to my closest friends and extended family as to why I couldn’t attend some family gatherings or why I was absent from school for weeks at a time. I also attended an elementary school where the main population was white. (Morgan, 2020, para#3)

This concern around needing to “hide” the disease in order to be seen as “normal” is difficult for youth, particularly in formative years of trying to figure out identities and bodies.

He elaborates, “I grew up as everyone’s token black friend. There was a certain standard I had to uphold to avoid stereotypes, avoid petty sympathizers, avoid labels, and most of all avoid being outcast” (Morgan, 2020, para#4). Morgan shows that he grew up trying to be seen as “normal” as possible. To him, his elementary years taught him that his biggest yearning was to be normal, particularly around not having CF, Morgan elaborates:

I just wanted to be a normal kid who was able to live life not worrying about being able to breathe, not worrying about my daily calorie intake, and not worrying about getting sick from the slightest change in weather. I wanted to be like everyone else around me-healthy. (Morgan, 2020, para#5)

For Morgan, he experienced more health related problems around fitting in with CF than worrying about being Black. However, not everyone is that lucky to not have to worry about being racialized and disabled. As he entered high school, he did feel a little more accepted, he joined music groups such as choir and playing the saxophone. He did however, still feel like an outcast for coughing longer and not being able to have any fellow peers with the same condition, Morgan's view being: "some people looked like me, dressed like me, and talked and walked like me. But the bitter fact still remained: I was not healthy like my peers, and I still felt alone thinking I was the only one in the world with Cystic Fibrosis" (Morgan, 2020, para#8). He seems to struggle with looking for a community based around illness and disability. It's important to note here that he could have benefitted both from other Cfers and people of colour with CF. Eventually, Morgan did have a double lung transplant and it was through the check up phase that he discovered a Facebook group that catered to other people with CF that Morgan felt like he could relate to: "upon my acceptance to the group, I was finally able to find people who lived the same life I had been living from birth. This Facebook page was the gift that I've been wishing for a very long time. This was my CF/transplant family" (Morgan, 2020, para#10). He finally found a way to connect with people who have this condition and it helped him feel less alone with cystic fibrosis.

Another area of medical tension around representation and CF is identifying as part of the Trans community. It is something that is not included enough in any ongoing dialogue around cystic fibrosis and gender formations in patients.

Being transgender is a risk factor if you have CF. It is known that the morbidity rate of CF is higher for women, due to levels of estrogen that cause significant inflammation. More

conversations need to take place on how patients with CF deal with male to female transitioning in relation to hormones and worsening of pulmonary symptoms. In “Worsening Pulmonary Outcomes During Sex Reassignment Therapy in a Transgender Female with Cystic Fibrosis (CF) and Asthma/Allergic Bronchopulmonary Aspergillosis: A Case Report”, by Lam, Goodwin, Wilcox & Quon, it is noted:

Here, we present a unique case of a patient with relatively stable CF lung disease complicated by both asthma and ABPA who then experienced a rapid decline in lung function and increased frequency of PEx temporally corresponding to rising serum levels of estradiol as part of ongoing sex reassignment therapy. (Lam et al. 2020, p.2)

If someone who has CF is going to undergo sex affirming surgeries, this increased risk factor must be considered. These risk factors are heightened even further for someone who is marginalized further as both trans and racialized.

Further, a grave concern that can produce fatal consequences is the underrepresentation of minorities in pharmaceutical trials taking place. McGarry and McColley write:

For many drugs, there are known racial and ethnic differences in therapeutic responses, drug metabolism, and adverse effects. One-fifth of new drugs approved between 2008 and 2013 for use in the United States were known to have significant racial and ethnic differences. In addition, participating in clinical trials may have direct benefits to study subjects, because clinical trial participants often have improved outcomes regardless of treatment allocations. (McGarry & McColley, 2016, p.1722)

These differences in race and ethnicity in regards to CF needs to be better addressed in current medical research. For example, there are significant benefits that can be attained when diverse groups are an active part of trials for new drugs. McGarry and McColley further observe:

Inclusion of minority patients in CF pharmacology clinical trials may be important to understanding differences in clinical responses to drugs. Accordingly, we undertook this study to investigate the reporting of minority subjects and the inclusion of minorities in pharmacology clinical trials for the treatment of CF reported over the past fifteen years. (McGarry & McColley 2016, p.1722)

It is necessary to include non-white groups in clinical trials so that the larger populations can benefit from new medications. The results show that racialized people are underrepresented: “between 1999 and 2015, 147 pharmacology clinical trials tested potential treatments for CF. Among these trials, 19.7% (29 of 147) reported the race and/or ethnicity of subjects. Latino subjects were reported as included in 7.5% of clinical trials (11 of 147) and Black subjects were reported in 6.8% of clinical trials (10 of 147). Only three clinical trials reported Asian subjects (2.0%). In 7.5% of trials (11 of 147), an “other” race/ethnicity category was reported” (McGarry & McColley, 2016, p.1722). McGarry & McColley show that there is a disproportionate amount of registered CF patients and those represented actively in trials.

Their work addresses the issues of accessibility to these studies for minority groups seeking to participate, the article describes the following:

Pharmaceutical companies and investigators should not only report the race and ethnicity of subjects, but also prioritize the inclusion of minority subjects in therapeutic studies of CF. Investigators should consciously design and conduct clinical trials in a manner that maximize the participation of minorities to whom new therapies may be prescribed. Study questionnaires should be translated into Spanish or other appropriate languages and should be administered by native-speaking interpreters or study staff. (McGarry & McColley, 2016, p.1724)

Allowing for unique approaches to include minorities will help involve marginalized groups to be a part of medical research around cystic fibrosis.

### **Sociological Depiction of Illness**

The pervasive belief that most people with CF are “ill” and may forever be seen in that light is a dominant narrative around this disease. This perspective reflects the conventional way that functional sociologists view illness, particularly as evidenced by Talcott Parsons’s idea of

the “Sick Role.” Parsons argued that anyone who is deemed ill is “outside of the norms of society.” This eventually becomes the “Sick Role theory” in sociology:

Parsons sees illness as a form of deviant behaviour within society, the reason being that people who are ill are unable to fulfil their normal social roles and are thus deviating away from the consensual norm. Parsons argued that if too many people claimed to be ill this would have a dysfunctional impact on society, therefore entry into the “sick role” needed regulating. Parsons, therefore, devised a “sick role mechanism” of how ideally a doctor and patient should interrelate. Within this mechanism, ill people and doctors had to abide by a number of “rights” and “obligations” attached to their respective roles in order to keep entry into the sick role tightly monitored. The “function” of this mechanism was to prevent what Parsons called a “subculture of the sick” from developing. Individuals who claimed the sick role who were not actually ill were classed as “malingerers.” (Parsons, 1951, cited in Milton, 2004)

This theory is problematic from the perspective of anyone who may be battling a terminal illness.

While other sociologists have subsequently critiqued this theory, it remains an aspect of how illness is viewed in society. The prevailing notion around having CF is that you are seen as “ill” for the rest of your life. Parsons sees people as needing to be “fixed” as soon as possible. With CF, this is not the case, he fails to take into account anyone with a terminal illness, he dictates:

Obligations: 1) The sick person is expected to see being sick as undesirable and so are under the obligation to try and get well as quickly as possible. 2) After a certain period of time, the sick person must seek technically competent help (usually a doctor) and cooperate with the advice of the doctor in order to get better. (Parsons, 1951, cited in Milton, 2004)

Parsons’ take on the temporality of illness is what causes so much concern for anyone who is terminally ill, their desirability to be allowed to exist in society should not be impeded upon by being seen as being sick forever. This is a major problem for anyone battling CF. It is not a CF patient’s fault if they were born with this aggressive, terminal illness so to be deemed as “undesirable” is disheartening. Furthermore, if this is a lifelong condition, one can simply not

“get better as soon as possible.” Anyone with CF is followed closely by a specialized medical team that makes sure people can remain stable and function within society as normally as possible. Even with doctors’ orders and medications, being able to get better is not always possible.

### **Feminist Theory/Health/Critical Race/Queer Studies/Disability Studies/Intersectionality**

The sick role theory affects how people who are terminally ill are perceived because it is normalized into the collective consciousness of people both inside and outside of the CF community. Critical feminist health, race, queer, disability and intersectional lenses helps bring light to alternative ways of representing CF. Audre Lorde was a queer Black feminist whose work sheds light on racialized, queer and disabled bodies. In *The Cancer Journals*, her writings about having breast cancer, she discusses the silence around speaking out on having cancer and the ways in which prosthesis encourages that silence:

It is not my intention to judge the woman who has chosen the path of prosthesis, of silence and invisibility, the woman who wishes to be “the same as before.” She has survived on another kind of courage, and she is not alone. Each of us struggles daily with the pressures of conformity and the loneliness of difference from which those choices seem to offer escape. I only know that those choices do not work for me, nor for other women who, not without fear, have survived cancer by scrutinizing its meaning within our lives, and by attempting to integrate these crises into useful strengths for change. (Lorde, 1980, p. 10)

Lorde explains how one can either remain silent on how illness is perceived or one can speak up and begin to talk about the battles that come with a diagnosis of an illness. What society expects us to do while being ill is one of the underlying pressures many patients face. For her it is having to decide to have a prosthesis put in, to help her look “normal” once more, that this is what society demands you do to feel healthy and less ill. In the world of CF, most people, if they

are deemed healthy enough, are offered a lung transplant. Some say yes and others may deny the procedure. Many find the emotional, physical and psychological toll too demanding, or have other reasons as to why they cannot go forth with the operation. Others decide that they would rather die. This decision all relies on each individual person's case and of course family, doctors, surgeons, partners, children all have an input in this process. Lorde reminds us that a) the pressures of society should not be dictating how we choose to deal with an illness and b) that remaining silent on our experiences will not cease the inevitability of the reality of the disease, that for some, speaking up is crucial.

Through medical research on race and CF as well as some of the debunking of Parsons's theory of the "Sick Role" through Audre Lorde's work, there is substantial evidence that cystic fibrosis can be represented more holistically. Other feminists such as Dr. Kimberlé Crenshaw, Patricia Hill Collins, Sirma Bilge, Alison Kafer, Rosmarie Garland-Thomson, Nirmala Erevelles and Leah Lakshmi Piepzna-Samarasinha also help further the discussion along in terms of helping to refute a white, heteronormative view on CF. They do this through the theory of intersectionality and other fields that influence this theory which I will discuss in the next chapter.



## **CHAPTER 3: THEORY AND METHOD**

In this chapter, I describe the theoretical framework with which I approach my study of CF representations, and provide an explanation of the methods I have employed. In the first section, I present an exploration of the theory of intersectionality through works done by Kimberlé Crenshaw, Patricia Hill Collins and Sirma Bilge. This concept has been picked up by feminist scholars working in a number of fields. Intersectional theorists such as Sami Schalk speak to the importance of literary representation; Alison Kafer argues for the integration of disability and queerness into feminist epistemology. Rosemarie Garland-Thomson helps broaden intersectional theory by arguing for the integration of disability and feminist thinking. Nirmala Erevelles widens intersectional thinking by discussing Critical Race Theory and Disability Studies. Moya Bailey and Izetta Mobley discuss the integration of Black Feminist Theory, disability and race studies. Leah Lakshmi Piepzna-Samarasinha is important in my argument for bringing intersectional thinking into praxis with Disability Justice. In the last section of this chapter, I discuss my research methodology and strategies for analyzing CF representations and the methods I will use.

### **Theory: Intersectionality**

In an article called, “Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of AntiDiscrimination Doctrine, Feminist Theory and Antiracist Politics”, Dr. Kimberlé Crenshaw describes her understanding of intersectionality in this way:

Consider an analogy to traffic in an intersection, coming and going in all four directions. Discrimination, like traffic through an intersection, may flow in one direction, and it may flow in another. If an accident happens in an intersection, it can be caused by cars traveling from any number of directions and, sometimes, from all of them. Similarly, if a Black woman is harmed because she is in the intersection, her injury could result from sex discrimination or race discrimination. (Crenshaw, 1989, p. 149)

The key in the above-mentioned scenario is to understand how Crenshaw uses the idea of an intersection of identity that can become busy with drivers of politics, race, sex, gender, illness and so on. She goes on further to drive the point on why Black women particularly, are still being excluded from feminist scholarship:

I argue that Black women are sometimes excluded from feminist theory and antiracist policy discourse because both are predicated on a discrete set of experiences that often does not accurately reflect the interaction of race and gender. These problems of exclusion cannot be solved simply by including Black women within an already established analytical structure. Because the intersectional experience is greater than the sum of racism and sexism, any analysis that does not take intersectionality into account cannot sufficiently address the particular manner in which Black women are subordinated. (Crenshaw, 1989, p. 140)

This need to understand a Black woman's perspective is a driving force for this project within an intersectional framework. Crenshaw also notes the importance of how reform impacts women of colour. In her essay titled "Mapping the Margins: Intersectionality, Identity Politics, and Violence Against Women of Color," she comments: "women of colour are differently situated in the economic, social and political worlds. When reform efforts undertaken on behalf of women neglect this fact, women of colour are less likely to have their needs met than women who are racially privileged" (Crenshaw, 1991, p. 1250). This is key in understanding a Black woman's perspective on cystic fibrosis. She along with other scholars has helped to bring a deeper understanding and need for intersectionality.

More work done by feminist scholars of colour on intersectionality can be seen through the works of Patricia Hill Collins and Sirma Bilge. In their book, *Intersectionality*, they discuss some key aspects of this framework:

Intersectionality is a way of understanding and analyzing the complexity in the world, in people, and in human experiences. The events and conditions of social and political life and the self can seldom be understood as shaped by one factor. They are generally shaped by many factors in diverse and mutually influencing ways. When it comes to social inequality, people's lives and organization of power in a given society are better understood as being shaped not by a single axis of social division, be it race or gender or class, but by many axes that work together and influence each other. Intersectionality as an analytic tool gives people better access to the complexity of the world and of themselves. (Collins & Bilge, 2016, p. 2)

Intersectionality is an analytical tool to understand how people's lives are affected by a multitude of social relations such as class, race, sexuality, ethnicity, migration status, and gender. These social systems create privileges for some people, and barriers and oppressions for others. They also tend to intersect one another as well, such as race and gender. An example of this would be someone who has CF and is Black and a woman: how this Black woman will interact with the medical system and the disease will be very different than a white man. Especially where research is concerned, there is still less work being done on Black genetic codes of the illness and this privilege of gaining treatments and cures is an ongoing concern. There are forms of oppression and privilege, all interacting differently depending on the subject, context, and location.

Viewing oppression and discrimination through an intersectional lens opens our intellectual capacity to formulate the ways in which people's lives are constantly shaped by gender, sex, sexuality, race, ethnicity, class, education, religion, age, language, (dis)ability and any other social identity that is designated as inferior and/or a minority within a patriarchal, capitalist, imperialist, white-male-supremacist society. It is also important to note that each

social identity is not a monolithic group where everyone experiences oppression, domination, or discrimination in the same way. Intersectionality is the lens through which we can see and begin to understand the whole person and the various groups of oppressions and privileges that each encounter at any given time and how these can flow like ebbing water, overlapping one another, alternating with each social situation one is placed into.

The work of Crenshaw, Collins and Bilge on intersectionality helps to develop a different perspective on the dominant white, heteronormative representation of CF. While the work of intersectional feminists is important, few talk about disability or illness directly in the way that Lorde (1997) does. Not enough intersectional feminists of colour explore disability and illness adequately in their work. Rosemarie Garland-Thomson, a feminist disability scholar, is writing on the importance of integrating other fields into feminist thinking, such as disability studies. As Garland-Thomson notes, “[m]ost fundamentally, though, the goal of feminist disability studies ... is to augment the terms and confront the limits of how we understand human diversity, the materiality of the body, multiculturalism, and the social formations that interpret bodily differences” (Garland-Thomson, 2002, p. 3). Feminist disability studies in relation to intersectionality is very important as it offers a non-mainstream feminist view on how the body functions in social spaces. The intersection of disability, race and queerness is further examined by writers including Nirmala Erevelles (2011, 2010), Schalk (2018), Kafer (2013) Garland-Thomson (2002), Bailey & Mobley (2018), Lorde (1980) and Piepzna-Samarasinha (2018).

## **Disability and Feminist Theory**

**Sami Schalk**

In her book called, *Bodyminds Reimagined: (Dis)ability, Race, and Gender in Black Women's Speculative Fiction*, Sami Schalk explains her take on the field of disability studies: “disability studies is the interdisciplinary investigation of (dis)ability as a socially constructed phenomenon and systemic social discourse which determines how body, minds and behaviours are labelled, valued, represented and treated” (Schalk, 2018, p. 3). While this is an important field of study, she notes that it must be approached from an intersectional perspective:

Intersectionality is a term generally used to describe both how people experience multiple social systems at once and a scholarly approach to analyzing and researching this multiplicity of identities, oppressions, and privileges. Typically, intersectionality is used to reference major social identities that are created within systems of privilege and oppression, including race, class, gender, sexuality, (dis)ability, age, nationality and ethnicity. (Schalk, 2018, p. 7)

Intersectionality is a useful tool that can help bring about an understanding around power relations within a system Schalk writes: “I understand intersectionality as an epistemological orientation and practice that is invested in coalition building and resistance to dominant structures of power” (Schalk, 2018, p. 8). The current power relations surrounding the everyday image of CF is what intersectionality is helping to explore further.

Schalk addresses race, gender and sexuality with an interesting take on stories of science fiction: “what if Steven Jameson, white, male, heterosexual, hyper-able chosen one of the Tomorrow People were black, and female and alone in this particular experience of reality” (Schalk, 2018, p. 60). If science fictional literature were to have more representational aspects of dynamic power relations around disability, race and gender, perhaps we could see these power relations unfold in a real world setting around characters dealing with compounding societal aspects of illness.

Another good point she makes is around illness and social issues, “no diagnosis is actually unproblematic or freed from social and cultural issues” (Schalk, 2018, p. 63). In a world of societal privileges and oppressions, a diagnosis comes with many factors to consider that will impact how an individual can survive an illness.

Schalk also discusses how our minds are intrinsically connected to our bodies, that we cannot impact one without impacting the other. Rather than compartmentalizing experiences of body and mind, Schalk sees them as fundamentally connected. To explore this, she borrows a concept from disability studies scholar Margaret Price (2015)-- the concept of “bodymind”:

The term *bodymind* insists on the inextricability of mind and body and highlights how processes within our being impact one another in such a way that the notion of a physical versus mental process is difficult, if not impossible to clearly discern in most cases. (Schalk, 2018, p. 5)

In today’s world, this term needs to be paramount in gaining a deeper and encompassing understanding of the intersections of our bodies and minds and the impacts that can be attributed to both even if just one is affected.

### **Alison Kafer**

Alison Kafer specialized in a field of feminist research called “queercrip.” Queer crip is the study of looking at the queer community through a lens of taking back the term “cripple.” I use Kafer as an important feminist scholar who brings about the urgency around a more complex definition of “feminism.” Kafer discusses the pressure parents face when deciding to keep a child with a disability, she states, “the pervasiveness of prenatal testing, and especially its acceptance as part of the standard of care for pregnant women, casts women as responsible for their future children’s able-bodiedness/able-mindedness; prospective parents are urged to take

advantage of these services so as to avoid burdening their future children with any disabilities” (Kafer, 2013, p. 69). Once you are pregnant with a child, parents are able to allow for CF screening, but the risks run high of deciding to abort due to illness. In a society that views the disabled as non-performative to the capitalist system, newborn screening comes with a host of problems around parents being prepared to provide care for someone who is deemed terminal.

### **Rosemarie Garland-Thomson**

Feminist thinking has over the years evolved into numerous differing ideals on what constitutes “feminism.” One aspect that needs to be considered for a more intersectional view on feminism is the area of disability studies. Rosemarie Garland-Thomson is a notable disability studies theorist who is a researcher in this area and has been a proponent of advocating for the importance of both fields to converge. In an article titled “Integrating Disability, Transforming Feminism,” she states some key aspects of the importance of this merger: “This is not to say that feminist theory can be transferred wholly and intact over to the study of disability studies, but it is to suggest that feminist theory can offer profound insights, methods, and perspectives that would deepen disability studies” (Garland-Thomson, 2002, pp. 1-2). There may be some very unique and important aspects that disability studies can learn from the field of feminism. Furthermore, Garland-Thomson notes that there are intrinsic topics that relate to disability that feminism isn’t always aware of:

Repeatedly, feminist issues that are intricately entangled with disability-such as reproductive technology, the place of bodily differences, the particularities of oppression, the ethics of care, the construction of the subject-are discussed without any references to disability. Like disability studies practitioners who are unaware of feminism, feminist scholars are often simply unacquainted with disability studies perspectives. (Garland-Thomson, 2002, p. 2)

Both feminist studies and disability scholarship needs to work collaboratively together in order to see more socially complex bodypolitics at play. Garland-Thomson draws on both to learn from one another, her view being:

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.” (Garland-Thomson, 2002, p. 3)

The pair have shown progress in definitions of respective topics in their fields, however, both can help put a critical lens to one another to help back up intersectional thinking.

She also speaks to the dialogue around the perfect body that Western society has been presenting, emphasizing the following: “the disability system excludes the kinds of bodily forms, functions, impairments, changes, or ambiguities that call into question our cultural fantasy of the body as a neutral, compliant instrument of some transcendent will. Moreover, disability is a broad term within which cluster ideological categories as varied as sick, deformed, crazy, ugly, old, maimed, afflicted, mad, abnormal or debilitated—all of which disadvantage people devaluing bodies that do not conform to cultural standards” (Garland-Thomson, 2002, p. 5). Disability studies can help to bring into view and focus the problems faced by people who do not fit this idea of an ideal body/mind.

There are multiple ways that the study of disability can help enhance feminist thinking, Garland-Thomson states, “the second domain of feminist theory that a disability analysis can illuminate is the investigation of the body: its materiality, its politics, its lived experiences, and its relation to subjectivity and identity” (Garland-Thomson, 2002, p. 9). By bringing the two together, lived experiences have a much deeper meaning and appreciation for the body and recognize any able-bodiedness that may have been overlooked before.



How women and the ill/disabled are being seen is problematic. Disability studies, coupled with feminist thinking, can alert us to the fact that this villainization of the woman and illness needs to be addressed, Garland-Thomson notes:

Feminist disability theory offers a particularly trenchant analysis of the ways that 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 illness has entailed distinct consequences in everything from epidemiology and diagnosis to prophylaxis and therapeutics. (Garland-Thomson, 2002, p. 10)

It is an issue to medicalize the female body because it can leave many emotional/mental health effects on people.

Further, she addresses the issue of politicizing the body and the forced medicalization of it, trying to correct one thing could also cause a long-term disability along the way, Garland-Thomson remarks:

Feminist disability theory suggests that appearance and health norms often have similar disciplinary goals. For example, the body braces developed in the 1930's to ostensibly correct scoliosis, discipline the body to conform to dictates of both the gender and the ability systems by enforcing standardized female form similarly to the nineteenth-century corset, which, ironically, often disabled female bodies. Although both devices normalize bodies, the brace is part of medical discourse while the corset is cast as a fashion practice. (Garland-Thomson, 2002, p. 10)

The problem is that both the medical world and Western ideals of female beauty are pushing the limits to what it wants the body to look like. Not only is the female body undergoing medical experiments but it also then falls into line with these experiments to go along with what the beauty world wants to see in order to capitalize off of these procedures. This leading to the ever present world of medical/beauty coming together to make and modify female bodies, Garland-Thomson states:

Cosmetic surgery's twin, reconstructive surgery, eliminates disability and enforces the ideals of what might be thought of as the normalcy system. Both cosmetic and

reconstructive procedures commodify the body and parade mutilations as enhancements that correct flaws to improve the psychological well-being of the patient. (Garland-Thomson, 2002, p. 10)

The commodification of a female body is bringing in a great deal of money but not always a sense of well-being.

Notable feminist Audre Lorde is highly against reconstructive/cosmetic surgery due to breast cancer. Disability studies coupled with intersectional feminist thinking can help to have a more fruitful discussion on why not every woman who is enduring breast cancer is in need of these types of surgeries. Lorde wants to show her scars and show that she is different, she does not feel so inclined to be a part "of the norm." Garland-Thomson also notes the same when it comes to what cosmetic surgery is really pushing for:

The purpose of aesthetic surgery, as well as the costuming of power, is not to appear unique-or to "be yourself", as the ads endlessly promise-but rather not to be conspicuous, not to look different. This flight from the nonconforming body translates into individual efforts to look normal, neutral, unmarked, to not look disabled, queer, ugly, fat, ethnic, or raced. (Garland-Thomson, 2002, p. 11)

Body alterations are set up to prey on people's insecurities and their wallets. In a world so engrossed in outer beauty, we must not forget qualities such as resilience that are used to overcome cancer.

It is ceaselessly driven into cancer survivors that a reconstructive surgery will help them feel better about their bodies. In relation to feminist thinking and disability, it is important to see the prevalence of continued ableism in medicine, particularly in the world of prosthesis. Unless it is a necessary limb that needs to be brought in in order to fully function, the female breast is not a necessity per se. It has been sexualized for years and once it is gone, a woman can be reduced to feeling she is no longer beautiful. This is all highly damaging and only breeds further

toxic ideologies around women's bodies. Garland-Thomson calls this the "politics of prosthetics", she notes:

In addition, the politics of prosthetics enters the purview of feminism when we consider the contested use of breast implants and prostheses for breast cancer survivors. The famous 1993 New York Times Magazine cover photo of the fashion model Matushka, baring her mastectomy scar or Audre Lorde's account of breast cancer in *The Cancer Journals* challenge the sexist assumption that the amputated breast must always pass for the normative, sexualized one either through concealment or prosthetics (1980). A vibrant feminist conversation has emerged about the politics of the surgically altered, disabled breast. (Garland-Thomson, 2002, p. 12)

Garland-Thomson utilizing Audre Lorde's work is crucial to see how the medicalization and beautification of the female body impacts those who are ill.

In completion of these thoughts, Garland-Thomson gives some compelling arguments/points as to the importance of integrating feminist thinking along with the discourse of disability studies. Both help the other to become stronger in facing systemic and societal challenges for subjugated groups.

### **Nirmala Erevelles**

Nirmala Erevelles is a professor at the University of Alabama whose research interests include Critical Race Theory (CRT) and disability studies along with sociology of education and transnational feminism. In her article that she writes with Andrea Minear called "Unspeakable Offenses: Untangling Race in Discourses of Intersectionality", she speaks on CRT and disability studies. She begins by referring to Critical Race Feminist Patricia Williams and some of her work, Erevelles notes:

In her essay, "Spirit Murdering the Messenger", Critical Race Feminist (CRF) Patricia Williams describes the brutal murder of a poor, elderly, overweight, disabled, Black woman by several heavily armed police officers. Trapped at the intersections of multiple oppressive contexts, Eleanor Bumpur's tattered body was quite literally torn apart by her

multiple selves-being raced, classed, gendered, and disabled. (Erevelles & Minear, 2010, pp. 127-128)

Erevelles shows through William's work, how a Black and disabled body can be unfairly and fatally impacted by race and disability.

Erevelles and Minear argue that intersectionality "can be utilized by both Critical Race Theory and Disability Studies to analyze the experiences of people located at the interstices of multiple differences" (Erevelles & Minear, 2010, p. 128). CRT and Disability Studies helps the area of intersectionality by looking at more complex interstices of marginalized people.

Another aspect of integrating these very necessary feminist fields into intersectional theory, is looking at how the idea of hierarchy plays into these areas:

Feminists of color have, therefore, had the difficult task of attempting to theorize oppression faced at the multiple fronts of race, class, gender, sexuality, and disability. (2) Thus, if one is poor, black, elderly, disabled, and lesbian, must these differences be organized into a hierarchy such that some differences gain prominence over others? (Erevelles & Minear, 2010, p. 129)

Within intersectional theory, if we readily include CRT and Disability Studies, these experiences can alter in differing contexts. There is no hierarchy of oppression because due to where one is situated in social systems, not all oppressions are treated the same. It is crucial that the only way to fully understand and be representative of all oppression systems is to include fields such as CRT and Disability Studies. Erevelles helps to see that CRT and Disability Studies are part and parcel of intersectional thinking.

## **Black Feminist Disability**

A Black feminist disability paradigm is a unique way of looking at both Black and disability studies and some of the missing pieces within both fields. It is the urgent need to bring both together in order to better unpack oppressional states from an intersectional perspective.

Authors Moya Bailey and Izetta Mobley speak to this framework by addressing the lack of intersectional understanding of both Black studies and disability studies:

By employing a Black feminist disability framework, scholars of African American and Black Studies, Women's, Gender, and Sexuality Studies, and Disability Studies have a flexible and useful methodology through which to consider the historical, social, cultural, political, and economic reverberations of disability. (Bailey & Mobley, 2018, p. 19)

It is imperative that differing fields consider the compounding effects of marginalized groups and how those oppressions impact people's lives. This specific knowledge paradigm is abundant in understanding the ways in which people's lives are inherently more complex than previously thought. The more that both the field of Black Studies and Disability Studies think about integrating themselves into each other's frameworks, the more chance there is of an intersectional understanding around race and disability, Mobley and Bailey state, "this framework highlights how and why Disability Studies must adopt a comprehensively intersectional approach to disability and non-normative bodies and minds and explains why Black Studies should do the same" (Bailey & Mobley, 2018, p. 19). From an intersectional perspective, people's lives are not a monolithic social experience and by embracing two very important fields together, it helps gage those experiences around multiple interstices of oppression. Further, a Black Feminist Disability framework helps to think about very solo theories working together, Mobley and Bailey suggest that "A Black feminist disability framework centers race, gender, and disability, challenging these generally siloed theories to

work together to better understand the realities for those multiply marginalized within society” (Bailey & Mobley, 2018, p. 20). I argue that breaking down the barriers to only seeing these social categories as independent theories is essential in understanding the varied ways in which people experience things such as gender, race and disability in compounding ways.

A Black Feminist Disability framework also makes us think to the ways in which ableism is and continues to be imposed onto marginalized groups. Specifically in the job market. The authors note:

Not only are some jobs debilitating, some people are unable to work. How might we reimagine our labor organizing if we do not assume that everyone should work to get their needs met? How might we restructure society itself if we could meet our needs without working jobs, however dignified and humane they might become? (Bailey & Mobley, 2018, p. 33)

Ableism of the job market is detrimental to the disability community. Adding in someone who is Black and disabled is what Black Feminist Disability is trying to address.

Both Black Studies and Disability Studies oppose the use of eugenic ideals and the detrimental effects on both the black and disability communities. Bailey and Mobley comment: “Disability Studies shares a strong critique of eugenic medicine with Black Studies. A range of scholars have recently addressed (and problematized) the difficult relationship between medicine and race, and the social versus medical model of disability” (Bailey and Mobley, 2018, p. 29). This problematization is critical in addressing the ongoing problems around medicine, race and disability.

How race and disability both have been used to impose restrictions on the other is unsettling in a societal context. Bailey and Mobley state, “Race-and specifically Blackness-has been used to mark disability, while disability has inherently “Blackened” those perceived as unfit. Black people were-and continue to be assumed intellectually disabled precisely because of

race” (Bailey & Mobley, 2018, p. 24). If we combine the ideas behind Black Studies and Disability studies, we can see how someone who is Black and disabled would feel extremely uncomfortable around being seen as “Black” and “Disabled” based around these notions of race and ableism.

From the beginning of the transatlantic slave trade, Black bodies have been notoriously seen as something to be acquired to help, “produce” work and have been heavily laden with anti-intellectual ideals. This eugenics factor is continuing to this day in ways that society is still profiting off of Black folks, Bailey and Mobley discuss:

Black bodies were assumed to be suited only to work, and not for freedom. From Thomas Jefferson’s assertion that Blackness inherently barred one from full cognitive citizenship, to the blossoming of eugenics in the nineteenth and early twentieth centuries that linked race and ability through scientifically racist theories that denigrated Black intelligence, Blackness has been consistently linked with lack and subhuman status. (Bailey and Mobley, 2018, p. 24)

The transatlantic slave trade set the stage for dangerous and toxic ideologies around being Black and how those bodies would be utilized for monetary gain by white supremacist slave owners that has slowly continued to trickle into our modern-day racist systems. Moreover, I argue that this capitalistic notion is an ongoing force that impairs the opportunity for anyone in the Black community to fully feel as an individual separate from the State’s financial and exploitive needs, the authors note, “much of the Black experience is shaped by an understanding of Black bodies as a productive labor force, leaving little room for an identity-based approach to disability” (Bailey & Mobley, 2018, p. 25). This constant need to assert a eugenic/ableist mindset around the Black community is detrimental in helping anyone to feel safe and taken care of in our current capitalist society. The authors go further in connecting the issue around being disabled and identifying as Black: “Ableism and notions of disability are a major component of anti-Black

racism” (Bailey & Mobley, 2018, p. 25). Therefore, I am arguing for the idea behind what a Black Feminist Disability framework can offer anyone who is Black and disabled, Bailey and Mobley elaborate, “we must recalibrate our expectations such that Black people are valuable beyond their ability to be productive to the State” (Bailey & Mobley, 2018, p. 26). For too long, the Black community has been utilized as a profit over people mentality from society and their disposability lacking being addressed.

Current day society has made it stigmatizing when someone is deemed both not able-bodied and Black. Bailey and Mobley address this further:

Designed to fortify Black children against the profound racism that is masked in a masquerade of meritocracy, this notion of having to be “twice as good” while often true, also marks the difficulties with discussing trauma, health disparities, and psychiatric or physical disabilities within Black communities. (Bailey & Mobley, 2018, p. 22)

A Black Feminist Disability framework allows us to see the importance of how psychologically damaging it can be for anyone who is growing up being Black and disabled, this feeling of shame is a direct impact of a predominantly white and able bodied societal ideology.

Bailey and Mobley directly speak to how a Black/disabled person will be treated by society, by arguing the following: “By bringing disability studies and a Black feminist theoretical lens to address this myth, scholars, are better able to explain Black people’s reluctance to identify as disabled and potentially offer new strategies for dismantling ableism within Black Studies” (Bailey & Mobley, 2018, p. 22). It is difficult enough to address battling racism, but just as important to look at the damaging factors around ableism as well and how these compound onto individuals.



I think it is also imperative that there is a discussion around how society views disabled folks, specifically the understanding around medical and social models of disability, the authors discuss:

The medical model of disability treats impairment as an individual that must be medically addressed. Something has gone wrong when impairment occurs, and there needs to be individualized medical care to restore the person to proper health through corrective surgeries, prostheses, and other forms of intervention. The social model, however, suggests that it is actually the way our society is set up that creates disability and inaccessibility. (Bailey & Mobley, 2018, p. 28)

Each model views disability in differing ways, the medical one only views the “individual” as the issue and not society as a whole trying to face a problem which the social model is attempting to address.

There is also a toxic myth around Black women who have been seen over the years as being “strong” women in the face of adversity. Any sign of weakness and this could be in the form of a disability, is then seen as problematic. Bailey and Mobley unpack this further: “the myth suggests that Black women are uniquely strong, able to endure pain, and surmount otherwise difficult obstacles because of their innate tenacity. Black women are disallowed disability and their survival is depoliticized” (Bailey & Mobley, 2018, p. 21). As shown, it is very toxic to place this sense of ableism on Black women.

### **Disability Justice**

Leah Lakshmi Piepzna-Samarasinha is a writer, poet, social activist, and educator from Oakland and Toronto. Her work chronicles stories of trans and queer people of colour, mixed-race people, abuse survivors and diasporic South Asians and Sri Lankans (Piepzna-Samarasinha,

n.d). She does this mostly under the framework known as Disability Justice. Piepzna-Samarasinha states one of the main tenets of this framework:

We know that we are powerful not despite the complexities of our bodies, but because of them....Disability Justice holds a vision born out of collective struggle, drawing upon the legacies of cultural and spiritual resistance within a thousand underground paths, igniting small persistent fires of rebellion in everyday life. (Piepzna-Samarasinha, 2018, p. 21)

Disability Justice (DJ) helps frame numerous struggles that help foster a sense of coalition politics.

DJ centers a great deal around survivorhood and drawing attention to the work and more specifically, the emotional work done by its followers. This “femme emotional work” though is not always seen as “real activism,” she notes, “It is under documented private work-work often seen as “not real activism.” But it is the realest activism there is. This is how disability justice art and activism change the world and save lives” (Piepzna-Samarasinha, 2018, p. 19). Without this femme emotional coalition work being done, many folks who lack community while they struggle could die, it is of the utmost importance that people find something to hold onto while they struggle through a system that only sees broken bodies as useless. Sometimes labels can help save lives, many people search for a long time to find a sense of community.

DJ has ten basic tenets that help define it as a framework, firstly designed by Patty Berne, intersectionality, leadership of those most impacted, anti-capitalist politic, cross-movement solidarity, recognizing wholeness, sustainability, commitment to cross-disability solidarity, interdependence, collective access and collective liberation (Piepzna-Samarasinha, 2018). In totality, DJ has what it needs to help bring more diverse dialogues around struggles.

DJ also brings into focus the issues around ableism that has been pervasive throughout history and how it affects groups of people, particularly the historical context around non-functioning bodies and the apprehensiveness of asking for “care.” Samarasinha states:

The Ugly Laws, on the books in the United States from the mid-1700’s to the 1970’s, stated that many disabled people were “too ugly” to be in public and legally prevented disabled people from being able to take up space in public. The Ugly Laws were interwoven with a mass creation in the 1800s and onward to hospitals, “homes”, “sanitoriums” and “charitable institutions” where it was the norm for disabled, sick, mad, and Deaf people to be sequestered from able-bodied “normal society.” (Piepzna-Samarasinha, 2018, pp. 38-39)

These laws are laying the groundwork for future dealings of how able body societies contend with the disabled. She notes that these laws eventually became major systems of power dynamics and how bodies are then used for a profit gaining: “these institutions overlapped with other prison/carceral systems, like residential schools, where Indigenous children were stolen, abused, and stripped of their language and culture, and prisons where Black, brown, poor, criminalized, trans, queer, and sex working people were locked up for profit” (Piepzna-Samarasinha, 2018, p. 39). The more that it is brought into focus on the problems that this model is causing, the more we begin to see why so many disenfranchised groups are not open to asking for care. Samarasinha goes on to say more in relation to this hesitancy around needing help:

People’s fear of accessing care didn’t come out of nowhere. It came out of generations and centuries where needed care meant being locked up, losing your human and civil rights, and being subject to abuse. The spectre of “the home” and lock up still haunts everyone when we consider asking or needing help. (Piepzna-Samarasinha, 2018, p. 39)

Generational trauma is a very real and a pervasive issue for many disenfranchised groups of people.

Samarasinha speaks to the idea of care webs that were designed by QTBIPOC (Queer/Trans/Black/Indigenous/People of Color). There is one particular model that she

elaborates on about the issue able bodied people have when they realize that their abled saviour complex of affording care may be invalid in relation to long term care. The able-bodied community can sometimes go into overdrive when someone who has never been disabled suddenly needs care and then realize that they do not know how to maintain that care, thus then reaching out to disabled groups asking for help, it is called the Crash and Burn Emergency Care Model, she remarks: “these models have a lot to learn from disability justice models of centering sustainability, slowness, and building for the long haul” (Piepzna-Samarasinha, 2018, p. 53). Many able-bodied folks tend to burn out quickly after someone becomes ill, hoping that they will “get better soon”, then find it difficult to deal with a long-term diagnosis. This is particularly true when dealing with the reality of never facing any issues with ableism, that there needs to be an open understanding and want to learn from those who are doing it their whole lives, her view being:

They need to understand that their friend isn't a special cripple, cooler than the rest-that the problems they're facing aren't individual ones but systemic struggles that face all crips and need collective solutions. They need to ask themselves why they have systematically refused to value or take in what disabled folks around them have been doing and are saying. (Piepzna-Samarasinha, 2018, p. 54)

When you are privileged enough to not have to worry about ableism and then need help with it, going to the next best known disabled person asking for help comes down to “how” you ask for help. If you are someone who is already aware of their struggles, then you will be the one person who is going to appreciate their help.

Piepzna-Samarasinha also draws attention to the concerns around independence and having needs. For many, asking for help means that your independence would be taken away, that they want to level the playing field in the system means that something has to be given up.

She describes how many try to still stay average, all while ignoring our needs, “Maybe as disabled people, if we wanted to have any kind of independence, we had to deny that we needed any help at all in order to stay in mainstreamed classes, go to college, or date, we had to say that we didn’t have any needs” (Piepzna-Samarasinha, 2018, p. 56). This loss of autonomy and agency over lives brings for many, an even more urgent sense of debilitation and a feeling that they are not worthy of accessing something while still holding onto their unique selves.

This also brings into focus the understanding that there is such a thing as, “crip emotional intelligence.” That having something to offer that goes beyond the capitalistic, ableist, white supremacist model of thinking around bodies. She writes:

It meant something to name and talk about all the crip skills I was seeing and learning that I and other disabled folks had. It meant something because, well, the deficiency model by which most people view disability only sees disabled people as a lack, a defect, damaged good, in need of cure. (Piepzna-Samarasinha, 2018, p. 69)

It allows folks with incurable illnesses or disabilities to question as to why they need to feel “cured” so they are able to offer something to the world. It also points to a way that disabled people might communicate with one another, from one disabled body to the next, in full understanding of limitations of each other’s disabled lives. Perhaps now, their very existence through the standardized limitations brings about new ways of thinking, doing and revolutions etched onto people’s bodies. The same can be said in relation to people dealing with invisible illness. In our society, many people still only view a physical disability as a means to amass care, leaving those out with mental health conditions and other invisible illnesses.

Many organizations and institutions have surface level representation but lack a critical systemic understanding around accessibility, the author remarks:

I know that if they do those things, without changing their internal worlds that see disabled people as sad and stupid, or refuse to see those of us already in their lives, they can have all the ASL and ramps in the world, and we won't come to where we're not loved, needed, and understood as leaders, not just people they must begrudgingly provide services for. (Piepzna-Samarasinha, 2018, p. 76)

It takes much more than surface level representation to happen if organizations want to show new and ongoing integrity in relation to the disabled community. She continues:

When abled people get ASL and ramps and fragrance-free lotion but haven't built relationships with any disabled people, it just comes off like the charity model once again-*look at what we're doing for you people! Aren't you grateful?* No one likes to be included as a favor. Inclusion without power or leadership is tokenism. (Piepzna-Samarasinha, 2018, p. 127)

Building relationships and bridges between the abled and disabled matters a great deal, particularly in regard to lessening the feeling of sympathy/charity that has been ongoing.

It can also be difficult for people to fully understand Disability Justice and how to “do it” properly, Samarasinha adds: “disability justice, when it's really happening, is too messy and wild to really fit into traditional movement and nonprofit industrial complex structures, because our bodies and minds are too wild to fit into those structures (Piepzna-Samarasinha, 2018, pg.124). This is the point of the movement, to not be seen as a “standard” care system.

Disability Justice is as unique as the communities it is helping.

Care work also begs the question, will we die young due to inadequate care work being done? The answer is a contentious one, Samarasinha thinks, “As I hear my friends talking about how they're sure they'll die young, I wonder if changing the narratives around care might change their expectations of dying young” (Piepzna-Samarasinha, 2018, p. 131). When communities have been made to believe that the current systems of care are only seeing their bodies as something to eventually dispose of, DJ helps to make people feel like they can live better and

longer lives based around their specific needs and so forth. As the author notes, a hallmark of Disability Justice is to not leave anyone behind, she comments:

This innovation, this persistence, this commitment to not leaving each other behind, the power of a march where you move as slowly as the slowest member and put us in the front, the power of a lockdown of scooter users in front of police headquarters, the power of movements that know how to bring each other food and medicine and organize from tired without apology and with a sense that tired people catch things people moving fast miss-all of these skills we have. I want us to know that-abled and disabled. (Piepzna-Samarasinha, 2018, p. 126)

Wolves are a prime example of a group who let the older and the sick lead their packs, something that the human race can learn from. The author says that part of “dreaming” disability justice is making sure the right people are involved in our futures, Samarasinha says:

With all of our crazy, adaptive-devices, loving kinship and commitment to each other, we will leave no one behind as we roll, limp, stim, sign, and move in a million ways towards co-creating the decolonial living future. I am dreaming like my life depends on it. Because it does. (Piepzna-Samarasinha, 2018, p. 135)

Care work shows us that every person has a unique ability to change this world and should be allowed to do so, fully and unapologetically in whatever form they so choose. Many communities’ survival depends on this de-structuring of current capitalist/colonial frameworks. It is work being done that helps us frame the idea of “prefigurative politics”, Samarasinha maintains: “prefigurative politics is a fancy term for the idea of imagining and building the world we want to see now. It’s waking up and acting as if the revolution has happened” (Piepzna-Samarasinha, 2018, p. 149). This imagery around building a better world where the marginalized are offered adequate access is a current ongoing process.

For so long, society has made many people feel as if they could not be “the norm.” It is in our current times that being different is the key to feeling fully immersed in one’s own honesty to the self, she notes: “we don’t know how to let people be both gifted and imperfect”

(Piepzna-Samarasinha, 2018, p. 177). It is the understanding of celebrating the imperfection along with the gifts. That the imperfection that was told needed “fixing” can now be allowed to flow, create, express and fundamentally, live and exist. That the differences and complexities are making the world a better and a more beautiful place, an accessible space. For many, dying was sometimes the only means of garnering agency away from the system controlling every aspect of their lives.

The current world model shows us that if you can’t produce something that you are seen as useless, Samarasinha suggests: “Capitalism says that disabled, tired bodies that spend too much time in bed are useless. Anyone who cannot labor to create wealth for owners is useless. People are valued only for the wealth they labor to build capitalism; crips are useless to capitalism” (Piepzna-Samarasinha, 2018, pp. 181-182). Capitalism has for many decades made the disabled feel extremely inadequate, capitalism equals ableism. She comments, “I am a chronically ill queer of color artist, and so much of my time is spent in my bed, heaped with cushions, is my office, my world headquarters” (Piepzna-Samarasinha, 2018, p. 182). In current times, working and living from home is a new normal, there can be a lot learned from those who have been needing to do it all their lives. Samarasinha writes: “I think that anger is valid, and that many people, particularly Black, Indigenous, people of color, queer, fat, working-class, and disabled people, get told we need to say it nicer when we’re mad at things that aren’t right, and that kind of tone policing is wrong” (Piepzna-Samarasinha, 2018, p. 217). For many disenfranchised groups, speaking up on issues that matter to their communities is seen as being too “loud.” It is the volume of the call outs that make the privileged uncomfortable.



While none of the theorists I have discussed above directly examine CF, their work on disability, illness, and the body is central to my project. Lorde is critical to my thinking about illness, race and queerness. Crenshaw, Collins and Bilge's theorization of intersectionality is central to my approach. Erevelles, Kafer, Garland-Thomson, and Schalk provide a way of thinking about intersectionality in relation to CRT, disability studies, queercrip, and race. All of them are crucial to my work as they provide a conversation around bringing disability and the body together with intersectionality. Some of them, particularly Schalk, pay a great deal of attention to literature and representation. Lorde and Piepzna-Samarasinha are important in that they show how it is necessary to talk about and centre the self in reflection around these issues. I will be drawing from these theorist's works to help analyze media, i.e CF Canada webpage and *Five Feet Apart* (2019) as well as literature, i.e *Transplanted* to help connect their intersectional ideas to the lack of representation in the CF community.

## **Methodology and Method**

My methodological approach in this thesis centers marginalized voices and questions their non-representation in images and narratives. I chose to use a feminist methodology that approaches disability, race, gender, sexuality, and class as co-existing and intersecting categories. This intersectional approach is paramount because it is not possible to separate CF or any illness without taking into account the body's other experiences of social difference. Fundamentally, I am challenging the exclusion of oppressed voices to the ongoing narratives around the condition known as cystic fibrosis.

My approach is also interdisciplinary and draws on methods from three disciplinary areas: Content Analysis (sociology), media analysis (cultural/communication studies) and literary analysis (literature). I developed a specific group of questions that arose from an intersectional feminist framework and a disability justice framework. These questions help me analyze representation through my “texts” which are the webpage, film and memoir. Very specifically, representational questions around race, class, gender, sexuality and disability/illness. Also, as these are differing forms of texts/mediums, it is key to think about them all on different levels of how information is conveyed.

I began research on this project in 2019, in preparation for my thesis proposal. I have been observing the CF Canada web page since Fall of 2017 and been able to observe changes connected with significant media events like the Black Lives Matter movement, the ongoing Trikafta negotiations and the global Covid-19 pandemic. 2019 was also when the film *Five Feet Apart* was released, and there was increased media attention on CF.

Over a period of seven months in 2019-2020, I watched the film *Five Feet Apart* several times. I watched the film in its entirety at least three times. On some occasions, I reviewed specific scenes in the film. With each viewing, I considered them in relation to the questions discussed below. I also read the book on which the film was based.

I read *Transplanted* (2019) twice over the course of two months. In the first reading, I read it all the way through and made notes along the way. On my second reading, I reviewed the book alongside the same specific questions about intersectional representation that I used to analyze the film.

## **Content Analysis**

In my analysis, I approached each text with the following questions in order to stay consistent in regards to analyzing these forms of representation.

- 1) Are people of colour represented? How many? What kind of roles do they have? Are they centered or marginal? How are people of colour represented?
- 2) Are there any queer representations? What kind of roles do they have? Are they centered or marginal? How are they represented?
- 3) Is economic class represented? How is economic access or wealth represented? Are financial struggles reflected?
- 4) Are the challenges of mental health considered and their repercussions? How is it addressed?
- 5) Is immigration mentioned throughout the works? How is it seen/represented?
- 6) How much does family get spoken of? Support? Who counts as family?
- 7) Is the struggle of searching for safe and adequate housing explored? What KIND of housing struggles?
- 8) Is insurance considered? What kind of concerns? Access to insurance? Who gets insurance?
- 9) Is gender considered and how is it considered? Do men/women get treated differently?

## **CF Stories in Diverse Mediums**

As each of the texts I have chosen are in a different medium, I am drawing on media studies and literary studies approaches to consider their differences.

In my approach to the CF Canada web page, my analysis focused on how people and their experiences were represented in both photos and text. I considered how the visual and textual elements were formatted and located, and which images were most prominent. I considered the intended audience: does the site speak to all genders, races and class backgrounds? What about differing generations? Is it adequately showing parents, grandparents, teens, small children? What about immigrants? Refugees? Is this website solely run by a Canadian team? Are there any non-Canadian outside influences on the production and maintenance of this website? Does it look like a financial investment was made to bring the most up to date imagery/scientific research?

In my approach to *Five Feet Apart* (2019) I considered the representation of CF in film. How realistic is the depiction of hospitalization? How accurate are the depictions of the CF routine/meds/medical procedures? Does the script stay true to the original form of the story/book? Are there parts taken away/cut from the textual book narrative for the film? How invested does the cast seem in their acting abilities to show the real side of this illness? Does the film seem like there is an investment done in using the latest tech to visualize it? Is this a Hollywood based film or from another global cinema market? Who is this film geared towards: Clinicians/families/politicians/researchers? Are numerous genders/races considered? Is this film considered a low budget production? Who is the director tied to the project? Are their political views being shown in the film? How big is the release of the film? Hollywood premier or low scale release?

*Transplanted* (2019) is Allison Watson's memoir about her experience with a double lung transplant and subsequent diagnosis of cancer. To analyze this book, I considered questions of content as well as her style of writing. How does the author share their journey through a CF

transplantation? Does she use mostly first person narrative to describe her struggles/milestones? Is she depicting up to date medical information? Is she big on using adjectives to describe her journey/opinions? Has she published other works to date? What are her accomplishments with CF? What publisher did she use? What is her general background? Are there aspects that are missing from her transplant story? How does she speak on the topics of class/race/gender? Who would benefit the most from her story? How does she represent herself?

## **CHAPTER 4: ANALYZING THE SOCIOLOGICAL DEPICTION OF CYSTIC FIBROSIS**

In this Chapter, I am utilizing an analytical framework of intersectionality to unpack the current day social depiction around cystic fibrosis. I do this by addressing gaps of representation in the Cystic Fibrosis Canada webpage, the film, *Five Feet Apart* (2019) and the self-titled memoir, *Transplanted* by Allison Watson. I use Crenshaw, Collins, Bilge help to discuss how intersectional CF can be, I explore Lorde who shows us some examples of medicine, race, queerness and centering the self and the body. I study Erevelles who helps to think around Critical Race Theory (CRT), disability, body politic and a deepening of intersectional thinking. Drawing on Kafer spurs a dialogue around queercrip. I engage with Garland-Thomson whose work revolves around the integration of feminist and disability paradigms. I rely on Schalk who brings up intersectional representation in literature, specifically looking at race, gender, sexuality and bodyminds. Additionally, I also bring forth work done by Piepzna-Samarasinha around disability justice. Lastly, I am drawing upon research done throughout my literature review that also helps bring to light some of the issues around underrepresentation.

### **Cystic Fibrosis Canada Webpage Analysis**

The Cystic Fibrosis Canada webpage's work revolves around informing both the general public and clinicians/families/patients on information regarding trials for medications, the ongoing battle to gain access to modulators, fundraising events, upcoming community events, patient stories, and other forms of general information on the illness. Images on the site are

predominantly of white-presenting volunteers, parents, children and families in treatments, participating in drug trials, taking part in normal family routines, and fundraising. Missing here is any representation of more diverse stories.

On the current Cystic Fibrosis Canada webpage, specifically dated for 2021, there is only marginal representation of people of colour. As I discussed in chapter two in my literature review, there is current substantial evidence that this illness is affecting Black people. Stewart and Pepper note that if physicians are not made aware of this illness in Black populations, many will be misdiagnosed (Stewart & Pepper, 2016). Additionally, there is also research supporting the inadequate genetic screening practices that are leaving out Black genetics for diagnosing this illness, Schrijver, Pique, Graham, Pearl, Cherry, & Kharrazi mention that the current model being used for genetic screening of infants is lacking for inclusion of non-white populations (Schrijver et al. 2016). Teena Mobley is an example of someone who is currently living with CF but had a late diagnosis of the condition and has had to face death because of it (Caroline, 2020). Her story needs to be thought of when dealing with knowledge of this condition in the Black community. Moreover, McGarry and McColley mention that there is also a lack of representation of minority groups in clinical trials for drugs and modulators. They observe that inclusion of them is critical to helping understand drug reactions in specific groups who have this disease who are non-white (McGarry & McColley, 2016). They note further that there are known racial and ethnic differences in how these drugs impact the body, including adverse effects and metabolism (McGarry and McColley, 2016). Lujan and Dicarlo also speak to the issue around Black people and how they have been tested differently in the past with regards to lung function. “Race correction” on identifying lung capacity in Black folks is a direct racial

link in medicine with a racist backing, as noted, using race and biology can have disastrous effects on Black lives in terms of genetic differences (Lujan & Dicarlo, 2018). Overall, there can be constructive ways to speak to science and race, it can be used to progress scientific understanding/policies but society must stay away from using biology as bigotry, diminishing any groups of people through science is dangerous. There are good and bad reasons to look at race in terms of medicine in relation to how pulmonary affects Black people's lives.

Where CF can be a disability, the oppressions of race and ableism should also be considered to be mentioned on this webpage as research does show it is not just a white illness. There are populations who have CF and are non-white, these oppressions matter in how they will be treated with cystic fibrosis, both in research and society. Erevelles speaks to Critical Race Theory and disability as a means to further strengthen intersectional thinking around CF. She notes that our bodies hold many societal conversations around accessibility and that marginalized bodies can be brutally torn down by an inaccessible system (Erevelles and Minear, 2010). It would be more representative to include some discussions on the webpage around being disabled with CF while also dealing with racial tensions.

Upon further analysis, there is no outward showing of LGBTQ people who have CF, this could be a more covert representation however, it should be highlighted that folks with CF are also on the spectrum of queer/trans oppressions. Furthermore, there is no seen affiliation with LGBTQ groups that seem to be either directly volunteering or any corporate sponsors. Again, volunteers or anyone with CF may be queer but it is not an overt thing. Alison Kafer's theory of "queer crip" can play a large role in how a vital conversation piece is missing from the webpage.



She notes that many parents can feel helpless when knowing that a child could be born with an incurable illness, making them feel like they are forced to choose their child's disability and that genetic screening can cause problems in choosing to keep that life (Kafer, 2013). Genetic screening as noted before, is to help us know if a child will have CF, particularly around racial accessibility to knowing as well. However well-intentioned, screening can also cause moral and ethical concerns around inflicting oppressions onto a child, i.e race, disability or queerness. It would be good to see the webpage think more critically around genetic screening and perhaps think about how to utilize it effectively when dealing with CF. Lorde also speaks to queerness and medicine, while also being Black. Her battle with breast cancer can relate to someone who is Black, has CF, is queer and is perhaps worried about some of the health concerns around this disease. She talks about women needing to be seen as strong in a fight against a terminal condition, that there needs to be a continued fight in terms of toxins in our daily environments that can cause cancer and that having necessary surgeries to help combat cancer should be seen as victorious scars that help show resilience and not ugliness, particularly in a dominant cosmetic world (Lorde, 1980). This is important in relation to thinking about cystic fibrosis as Lorde helps represent the hypothetical example of someone who is Black, queer and a woman and who needs a lung transplant. Many people worry about the scarring afterwards but should try to remember that those scars mean you are surviving. These sorts of personal stories around CF would be essential to help bring more representation to media venues, i.e someone such as Audre Lorde's story could be featured on the webpage.

The main message that is being conveyed on the web page in terms of class is that it is mostly well-to-do folks who are either advocating, volunteering or sharing their individual

stories. The main financial struggle seems to be taking place with the acquisition of new and beneficial drugs to help either treat or cure CF. Class is a major concern for many people with CF, in terms of intersectional thinking, it can add a definite strain to other oppressions. It would be more encompassing if there were an addressing of those who are impoverished and have this illness who needed financial aid.

There are some personal stories of patients and families on the struggles of affording life while dealing with this illness. There is a section dedicated to CF Champions that highlight the struggles and triumphs of anyone with this disease. Kadeem Morgan is being shown on the webpage and his story helps highlight some of his struggles. He has actively grown up with CF and being Black but he also brings a conversation around tokenism (Morgan, 2020). Even though he was briefly being showcased in the Fall of 2020, it is still a token effect. Prior to the Black Lives Matter movement, the webpage had a predominantly white representation, it has a feel of performative activism/corporate lip service, meaning it only places POC bodies on display in order to “show” the world it is being representative but is lacking a deeper analysis of these people’s social struggles around this disease. Another current CF champion is Tamy Maily who is Black and is from Québec. Her mother, Nadia, discusses their experience around race and CF: “it was a shock, but, at the same time, when you find out something like that, the adrenaline kicks in. The doctors told us it was unlikely because we were Black, so they did the tests again. Tamy was almost two years old. She had the signs, but the doctors said I was worrying for nothing” (Cystic Fibrosis Canada, n.d). I argue that Maily’s story showcases the ongoing naivety around the Black community and this disease in the medical establishment. Had her mother not spoken up on this issue, many in the CF community would not know these crucial

facts around being Black and having cystic fibrosis. There is an ongoing narrative in medicine that Black folks have a higher pain tolerance and this can be a direct relation to ongoing and pervasive racism in medicine. Black families having to fight to have diagnosis done, particularly around medical doctors even considering a Black person having cystic fibrosis. Medical students and residents have been told that Black pain is different from white pain and thus endorsing an improper treatment course of action (Swetlitz, 2016). Not considering an illness when classic symptoms are presenting themselves is in my opinion, a direct form of this ongoing trope around Black pain, particularly when it revolves around diagnosing CF.

A key component of managing CF is supporting mental health. The CF Canada webpage does seem to acknowledge that on matters of mental health, there are some stories from families/patients on the concerns around certain anxieties, i.e, transplantation, outcomes of drug trials, and fear of dying. *Five Feet Apart* (2019) is also showcased on the webpage, continuing, as will be discussed later, the ongoing white narrative on CF. The website also has a drop-down menu of CF mental health resources available. In particular, the webpage does acknowledge and is advocating against what the government is currently continuing in an age-old mentality around keeping people who are not able bodied sheltered from society, as seen, the government only has a certain number of provinces listed who will give access to immunocompromised populations to gain access to a COVID-19 vaccine. This directly relates to institutionalizing immunocompromised people in their own homes longer than is necessary and actively denying them safe access to public spaces. As discussed in Samarasinha's work, this ableism has a long-standing history, relating back to the "Ugly Laws" and how this has been interwoven over the decades into forcing disabled folks into being hidden from society (Piepzna-Samarasinha, 2018).

Not prioritizing access to a lifesaving vaccine for a particular disabled community is the government actively engaging in ableism. However, it is very surface based info/resources and not enough elaboration on intersectional folks who may have this illness as there are other anxieties to consider. More substantial work is needed in order to bring a more intersectional gaze into mental health and other oppressions as there are other pressing factors that are contributing from the system that impact mental health and having CF.

In terms of immigration, the webpage is lacking a sense of foreign representation. It showcases mostly white, middle class Canadians. There is no direct mention of immigration or immigration related topics that can help navigate new families coming from abroad. Some can be seen on the volunteer aspect of the webpage, with a few exceptions and even then, it still seems very tokenized. There needs to be further work done on ethnic variances and lived realities of cystic fibrosis that is not being viewed on the Cystic Fibrosis Canada webpage, such as fighting to gain access to Canada's healthcare system, insurance concerns and other stressors not openly discussed of families/individuals coming from other countries who have this disease.

Many of the images depict families doing treatments, partaking in drug trials, staying in a hospital during admissions and some other activities. Amongst all the familial imagery, it would be good to also see a narrative around loss of social capital i.e family loss/orphans and how those people can navigate access around care and other aid they may need if they are on their own. Additionally, it is noteworthy to point out that currently 62% of CFers in Canada are adults, (Cystic Fibrosis, n.d) and many of them are not able to or even would like to have children. It would be good to also see some voices in that regard, most of the families that are

showcased are the parents who do not have this illness but the child does. There is a whole generation of CFers now growing up who do not share that familial sense around CF.

The webpage lacks an overall understanding to help patients maneuver through economic accessibility around housing, insurance concerns, full-time employment worries and access to CF care provincially.

In terms of housing struggles, there is no mention of this. Even though lung transplantation does require an eventual search for housing in larger cities and things such as molds/dust buildup need to be spoken of and how to avoid the pitfalls of slum lords and unsafe rental companies. Housing needs major consideration throughout a CFer's life, long before transplantation occurs. The webpage could be more inclusive to add an additional narrative and resource on more accessible and budget friendly and safe housing. It is very stressful and dangerous to live with CF when it comes to making sure homes are clean and adequate for long term survival rates of this illness.

A more direct dialogue around insurance should be taking place on the web page as well and addressing some of the nuances around gaining access to it. The only area currently where insurance is coming up is surrounding CF Canada's lobbying of the federal government to help make Trikafta publicly funded. Furthermore, most people need to fundraise for their new lungs. One of the main partners for CF Canada called KIN Canada helps to fundraise for people who are not able to do so on their own. Other corporations are involved with fundraising as they are aware of this struggle. Nova Scotia is the only province to date that offers full coverage of medications, hospital visits and CF related procedures. Moreover, because this province offers

such services, many more families/individuals are coming to NS to gain this access point causing more healthcare strain on the province's already stretched thin medical services.

Additionally, many people with CF may not be able to work full time, thus placing added socio-economic strain on their lives if hours are cut due to needing to put in many hours of work in fighting CF. As well as possibly losing access to work related benefits if full time hours are not maintained, depending on which industries they happen to work in.

Another concern is around other provinces in Canada where basic CF care is not fully covered and people have to find means to help offshoot those costs, again, impacting socio-economic status and potentially impacting lived outcomes of the illness. Many folks think that healthcare is free in Canada, however, it is not, particularly around this illness. This country still discriminates against pre-existing conditions when it comes to attempting to gain access on their own through private health insurance. The fact remains that both CF Canada and patient advocacy groups have had to beg and plead the federal government to help them gain access to modulators such as Trikafta, allowing us to see that the disabled in Canada, are still viewed as disposable.

In relation to gender, the webpage does not exhibit any representation of trans people and things seem very gender specific i.e, heteronormative. In recent studies, it has been shown that the CF community has patients who are transitioning and particularly, male to female patients can have worsening pulmonary outcomes (Lam et al. 2020). There needs to be more representation around the trans community and this illness and adequate resources made available such as financial, housing and mental health supports, just to name a few.

### ***Five Feet Apart* Film Analysis**

In terms of cinema/media, *Five Feet Apart* (2019), depicts angsty teen love around the health risk of remaining six feet apart at all times in relation to cystic fibrosis germ protocol. It mainly shows two heteronormative, white patients who, one is in the hospital for a drug trial and the other is awaiting a lung transplant. The film mostly caters to a long-time standing Hollywood trope around coming of age love and terminal illness/disability. There is much lacking in terms of broader patient experiences of CF.

In *Five Feet Apart* (2019), there are a number of people of colour including the following; a Latino male character who was cast by a Spanish actor. The character of Poe Ramirez however, is seen as more frail and not as good looking as the two lead characters. He is someone who eventually is killed off exhibiting the standard Hollywood trope of erasing minority characters. I argue that there can be more development in terms of Poe's character to explore an intersectional take on being a person of colour (POC), while also navigating this disease. For example, he could have been cast as a Black woman and have a much more complex body politic involved that intersectional thinking can explore around CF (Crenshaw, 1989). There is also a nurse that is Black, Barb, who is placed into an authority figure position and also has a stereotypical Black nurse demeanor. There is another Black marginal character who is a friend of the main character Stella called Mya. Along with another Black friend to the main character of Will called Jason who is also seen as a marginal role. Dr. Hamid is also another character of colour, who is the main doctor that both Stella and Will deal with in the film, again, she is ranked with authority. I see this movie attempting a performative activist view

and “represent” minority characters as a sign of the times, not because of any intrinsic value or adding more complex understandings around race and CF but to tokenize. I see the script being flawed in this regard for adequate racial understanding and inclusion around cystic fibrosis.

With regards to queer representation, Poe is the only character who is seen as gay. The script doesn't go into any elaborate details on some of his queer struggles as a gay CFer. In relation to this specific character, I feel that coalition politics can help him understand and feel more accepted because he can represent CFers who feel alone both with having this illness and being gay. Piepzna-Samarasinha speaks about disability justice and how without coalition building, many can feel left out and misunderstood or left behind (Piepzna-Samarasinha, 2018). Poe's experience, if developed further, can be a great way of speaking to the intersections of queerness and CF.

Additionally, class is also seen throughout the film. The main character of Will Newman is seen as being well off, that he can afford to be on a new drug trial for B. Cepacia, but it is something he doesn't always see as being a privilege, Stella reminds him of this: “do you even know how lucky you are to be in this drug trial?” (*Five Feet Apart*, 2019). Will may not be in a good place in terms of having B. Cepacia but he is able to have access to a potential new drug. He is still a heteronormative, white CF male in the film who has certain class privileges. I maintain that through an intersectional lens, class worries can be more represented throughout the film. In terms of housing, not a great deal is mentioned on this topic as the story revolves mainly around CFers being admitted to hospital. If the script had gone into a more detailed



account of these patient's lives outside the medical industrial complex model of housing that they are currently in, it can show some of the concerns around living conditions and how that can impact their lives.

*Five Feet Apart* (2019) speaks to some mental health concerns although I argue that it can be more fulfilling if it were coming from an intersectional framework. The main character of Stella Grant has many troubles that she tries to either overcome or deal with while she is going through an admission. One is her struggle with her parent's divorce. She even notes that her parents are stealing her grungy look while in hospital, she states, "You're too thin. Dad needs a bath. You guys are stealing my look!" (*Five Feet Apart*, 2019). She means this as a joke of course to her mom but they both become emotional as they realize her time is limited with her parents, bringing up the constant worry of dying. This also relates to her sister who is dead due to a climbing accident. Samarasinha talks about the need to change our current systems of care in order to let people feel like they may not have to die young (Piepzna-Samarasinha, 2018). Coming from an intersectional position, there can be more dialogue and narrative around what it is like to lose ongoing family support, i.e. social capital while fighting this condition. She also comes out to Will as telling him she has a control issue, this may or may not be a direct relation to her sister's sudden death. It also alludes to the fact that the film looks at both patients who are not putting in adequate effort to survive this illness and those who are dealing with needing the comfort of having control over the illness from progressing. One is super organized and on top of their treatments and the other feels that doing treatments is a waste of time, Will says, "Stella, nothing is going to save our lives, we are breathing borrowed air, enjoy it" (*Five Feet Apart*, 2019). Will's comment makes Stella uncomfortable and she begins to see how loosely he

believes in his life with this illness. This self-care tension is also seen when she tries to control Will and his regimen, he tells her, “I get that you have some-save-the-world hero complex going on, but leave me out of it” (*Five Feet Apart*, 2019). Looking at it from an intersectional perspective, these characters can be written to have more things to try and have to control, i.e finances, housing, avoiding racism, homophobia and other accessibilities, isms and phobias surrounding surviving not just an illness but also many other oppressive factors.

In terms of Will’s mental health, he deals with a father that is not present while growing up, he tells Stella on their walk to the pool one night, “a kid wasn’t a part of his plan” (*Five Feet Apart*, 2019). This could also show some of the mental health concerns he has in terms of dealing with an absent father who may have also left due to not being able to cope with a terminally ill child. As noted before, losing social capital takes a toll on people and as Kafer notes, we must be willing to accept the battles our children will face if they are born not able bodied (Kafer, 2013). Will spends most of his time coping with being in admissions by playing guitar, drawing, seeing his friends for visits, and spending time on the hospital roof enjoying the view and being with his own thoughts. Even though Will may be ill, he has a special gift for drawing, Samarasinha notes that society must learn to accept the gifted with the imperfect (Piepzna-Samarasinha, 2018). She also comments that a majority of people’s lives can be spent in bed trying to simply live (Piepzna-Samarasinha, 2018). Even though *Five Feet Apart* (2019) is based on teenage love, angst and coming of age, it does raise the question of how these CF patients will deal with the working world at some point. Samarasinha says that for many who are terminally ill, capitalism has made them feel useless (Piepzna-Samarasinha, 2018). Will also brings us to the issue many CFers face in terms of body image. When he asks to draw Stella, it’s

more symbolic to the discomfort around being terminal/showing visible signs of CF, “I want to draw you” (*Five Feet Apart*, 2019). Stella allowing him to do so, not only shows that she trusts him with how she looks but that she is not ashamed of her CF body. Lorde’s experiences around having a mastectomy and how her family will view her after is a connection to this (Lorde, 1997). I argue that women who are disabled can have a more difficult time in terms of accepting their bodies as beautiful even if there is potential damage on both the inside or outside, describing a sense of internalized ableism.

Poe also has some mental health concerns that he has to work through. One being that he struggles to keep relationships with non-CFers, which is a huge problem in the CF world, particularly around romantic relationships. He gets told in an argument with Stella, that he has always pushed away many people who cared for him, Stella proclaims, “they knew you were sick, and they loved you, you were the one who ran, every time, you ran!” (*Five Feet Apart*, 2019). This comes across as tone policing from Stella in regards to Poe’s struggles with dating able-bodied people, Samarasinha says that he has every reason to be upset about his able-bodied partners not sticking around for the long haul in terms of this condition (Piepzna-Samarasinha, 2018). It is critical to note that this is an ongoing concern for CFers due to the cross infection rates amongst themselves dating one another. Finding able-bodied partners for the long run can be hard. Poe also has some mental health worries when it comes to being an immigrant in America, in regards to intersectionality, he is dealing with being foreign, struggling with access to health insurance, without family present and the strain of this on his mental health. His deportation back to his home country is seen as being detrimental to his chance at surviving CF.

In terms of immigration, *Five Feet Apart* (2019) looks mostly at the character Poe as the main token of being foreign. The story doesn’t analyze deeply enough the struggles of being

from another country. There needs to be a much larger narrative and dialogue around critical race and disability. Erevelles comments that intersectional thinking needs to include race and disability in order to better understand interceding areas of multiple variances of people's lived experiences (Erevelles and Minear, 2010). Poe's journey as someone who is coming to America for CF care is lacking a more in-depth intersectional analysis around struggles of being foreign and having this illness.

In discussing the area of family, *Five Feet Apart* (2019) does have four variances of what is seen as "family." One is Stella's where her sister is gone and her parents are in a divorce, Will's consists of a single mom and absent father, Poe's is overseas and there is a sense of familial belonging amongst the CFers themselves. Intersectionality wise, that variance is good to see as it does not just focus on a typical "white, married, two children" kind of trope. This kinship that the three main characters share, is also what disability justice adheres to (Piepznasamarasinha, 2018). Knowing that the three main CF characters have a special connection can help remind the audience that for many able-bodied family members, CF can be difficult to relate to, especially in day to day dealing with this condition. Sometimes finding your own family amongst the CF community itself can help bring a sense of understanding around daily disability struggles and so forth.

In terms of insurance, all the main characters have their own sets of concerns in relation to accessibility to care. One area in particular raises the question around being ill and feeling like society is constantly making you feel like you need to be cured, which relates to Talcott Parsons's idea of the "Sick Role Theory" (Parsons 1951, cited in Milton, 2004). Will worries

that he is wasting insurance on trying to be cured: “what if it doesn’t work?” (*Five Feet Apart*, 2019). This can mean two things, 1) he worries he may die from the condition and 2) he feels pressure from society to be “normal.” Parson maintains that anyone deemed ill should always find a way to get better, but he does not consider those who are terminally ill (Parsons 1951, cited in Milton, 2004). For many with CF, constantly feeling like they need to be well/healthy is an internalized ableism that society has drawn from such sources as Talcott Parsons’s “Sick Role Theory.” It leads to many inner battles with folks from the CF community on how they deal with being terminally ill and their views on being disabled and not fully abled in the long term.

Gender in *Five Feet Apart* (2019) is not explored in a more socially complex manner. I argue that if the story is looked at from an intersectional view that speaks to feminism and disability, Garland-Thompson raises some great concerns. She says that if we combine both worlds, certain factors can be explored more openly such as the place of bodily variances, reproductive tech, specific oppressions, building of the subject, ethics of care, if they are all studied without a take on disability, feminism will lack a specific field of study and integration (Garland-Thomson, 2002). I think that one specific area that can be explored further for all three characters is reproductive technologies. Men with CF are missing their vas deferens and women have a harder time becoming pregnant. Even though, again, the film is based on younger characters, sex does come up and it would help to see a narrative around fertility and CF and how that impacts each character’s body politics.

### ***Transplanted Book Analysis***

In Allison Watson's book, *Transplanted: My Cystic Fibrosis Double Lung Transplant Story*, the author writes a compelling story around having a double lung transplant due to progressive complications from cystic fibrosis. Her work relays mostly a white, heteronormative view through the process of pre-op, during and post-op. Due to her positionality, it is limited in a more representational depiction of this medical procedure.

I will begin with how she experiences race. Throughout the memoir, there is no outward mention of race, no colleagues, no medical staff, or fellow patients who identify as non-white. Non-white populations exist with CF and seeing a POC author who also endures a transplant would show more representation around their lived experiences around this procedure. Additionally, in terms of literature, I would push it further by saying it would be beneficial to see POC 10% CFers write about their experiences of trying to gain access to modulators and other lifesaving CF medications. Hearing more of those stories around accessibility would help those specifically within the CF community with those compounding factors. As discussed earlier, there is a definite lack of POC representation in CF research, particularly around modulators with minimal numbers coming up in studies (McGarry & McColley, 2016). Having voices explore that kind of literature in terms of CF would benefit the struggle around representation.

In terms of queer experiences around transplant, Allison's memoir has limitations to this social identity. She mostly discusses her journey with her white, male partner by her side and coming from a white, cis, heteronormative gender formation. In terms of literature, Audre Lorde uses poetry as a means to discuss her life around being Black, queer, a feminist, a woman and having cancer. Having more CFers who can speak to oppressions through different literary

forms while fighting this disease would benefit many, particularly where Lorde also uses her poetry as a means to address action (Minamore, 2018). Watson is not a poet so her writing style is also limited. Lorde uses poetry throughout her journey of having cancer all while speaking to other oppressive lived experiences along this medical journey. She utilizes her words to help address some of the divisions within the world of feminism, particularly the issue around remaining silent on many oppressive fronts (Minamore, 2018). Watson is speaking up through her memoir but there are many oppressed silent voices of CF who also deserve to speak on what it is like to have this illness through literary means, particularly around noting queer experiences.

Lorde speaks to having an illness and navigating it through a queer lived experience, that when she is loved by women, she feels less worried about losing a body part, that most cancer societies and groups need to remember to focus less on things such as prosthesis and more on some of the more emotional aspects patients face with a cancer diagnosis (Lorde, 1980). The more representation that comes forth in terms of CF and queer experiences, the more we can begin to see and understand some of the more emotional trials of going through this condition and not what a medicalized system makes one believe their bodies should look like or to feel any less love for who they are.

In addition, socio-economic struggle does come up a few times in Watson's work. One specific area is the ability to be able to travel. It does not go into specifics in regards to whether or not she raises money for traveling or saved or how she offered the means to do so. She speaks on enjoying the process of researching and getting things ready for a trip which helps distract her from her CF battle (Watson, 2019, p. 17). She also mentions that there is a social worker who is helping gauge her support system and finances do come up, Watson mentions:

The team doesn't like going through the entire process only to have someone back out, so she does interviews to gauge a candidate's emotional stability and ability to deal with the situation overall. She asked about my support systems, both emotional and financial. I told her that I had a great support system and there was no need to worry. (Watson, 2019, p. 24)

She covers both the privilege of having family to support her but also that she is able to move forward with the transplant talks as she is financially able to do so. She does not go into a significant amount of detail on that front. Lacking here is a conversation around those who can not either financially afford new lungs or who are battling mental health concerns around the overall pressures of a transplant or who do not have the social capital to help support them through the process. It would be nice to see some more stories that could address the financial hardships that come from lacking other areas of privilege. She also speaks to the ability to be able to have a vehicle to use while staying in Toronto during her surgery, she says, "we debated whether having a car in Toronto was worth it and in the end I won out on the pro-car side. I thought it would be helpful for getting groceries or driving to the hospital on days I didn't feel well" (Watson, 2019, p. 29). What about a CFer who cannot afford a vehicle? What if on the days your body is declining, you still have to be forced onto public transportation while worrying about catching life threatening bugs before transplant because it is overcrowded? These financial struggles need to be addressed. Not everyone can simply afford a vehicle while living in a major city. Allison also discloses that she and her partner have to become creative in trying to see Toronto on a budget: "touring Toronto is easy to do if one has unlimited funds, which was, unfortunately, not our case. But we did find options for those of us with budgets if we looked and planned carefully" (Watson, 2019, p. 58). This is important that she acknowledges that not everyone can afford to see Toronto, including herself. She is able to tap into a resource that allows folks to gain access to Museums which really comes in handy to distract oneself while



waiting for new lungs, she notes, “the best program we found was through the city library, where we took full advantage of their Museum and Arts Pass (MAP) program” (Watson, 2019, p. 59).

Programs such as these can help folks who are struggling financially to still keep themselves engaged and busy while waiting in the city for medical treatments but for many, the intersection of class and lung transplantation is not adequately explored.

Watson speaks of the mental health struggles that she endures throughout her life so far with CF, particularly nearing transplantation, during her op and post-op. She begins by stating that for her growing up, she does use the term *disability* to identify herself, she observes,

I use the word *disability* in relation to CF and while other people may not like the word for themselves, I feel it is accurate for me. While having CF may not have caused me disablement when I was younger, it still limited my life in some ways. (Watson, 2019, p. 4)

Using the term disabled is different for everyone who has this illness, some don't use it until later when they struggle to maintain full time statuses and others use it their whole lives. In relation to intersectional thinking, things such as critical race theory, (CRT) and disability need to be considered when thinking about a non-white, disabled take on CF. This combination adds a depth to intersectional thinking that can help to address more mental health struggles related to health. Understanding how race and disability play into lived outcomes is critical (Erevelles and Minear, 2010). Watson goes into more detail on where to gauge what is considered able-bodied/disabled for CF, she notes, “it's hard to know where the line is. Having CF means you spend many days simply pushing yourself to get out of bed in the morning. It can be a struggle to do “simple” tasks like showering or cooking supper” (Watson, 2019, p. 6). For many, these oppressions of race and disability are a lifelong struggle, sometimes even compounded by both. Moreover, she speaks on the journey we are on in terms of the realization that our life will be

either limited or shortened due to a high morbidity rate of the illness, statistically speaking she says, “I’ve always known that having CF meant having a shortened life expectancy. But knowing the facts while healthy is different than having a doctor suddenly tell you that your options are to die in one to three years or take a chance with a lung transplant” (Watson, 2019, p. 6). Schalk (2018) mentions that no diagnosis is truly ever not impacted by societal factors that will influence someone’s survival.

She states how she feels the first time she is told that she will be needing new lungs, Watson observes: “when the doctor first mentioned starting the workup process for needing a lung transplant, I burst into tears and refused to talk about it. I was in denial about how sick I was and didn’t want to accept that I had reached the point of needing a transplant” (Watson, 2019, pp. 8-9). In a way, this is a feeling of finally being told you are dying, that your disability has reached a certain debilitating point. How disability is seen through other oppressions matters, how those bodyminds navigate news like that is where the importance of thinking of disability in an intersectional perspective comes in (Schalk, 2018). Trying to come to terms around being told you are dying is never easy, it takes a great deal of inner strength to face that realization. For many, due to society’s pressures, death always feels like it is a lived reality.

Luckily, she has the privilege of her workplace offering mental health counseling, she comments, “during that time, I was fortunate that I had access to my workplace’s mental health program. It gave employees access to counsellors either by phone, email or in face-to-face meetings” (Watson, 2019, pp. 9-10). In terms of gaining access to mental health services, not everyone has that option of those kinds of work benefits. If there are more marginalized people with CF producing literature and perhaps even in the genre of science fiction, on intersectional perspective on dominant power structures around who gets access to help, it would broaden the

scope of understanding CF from a viewpoint of lacking that necessary aid (Schalk, 2018). She also speaks on the waiting game of the transplant testing where she remarks:

Waiting for the results of transplant testing is a mind game. Like I've said, you have to be sick enough to require the transplant but healthy enough to survive the surgery and rehabilitation. You also have to not have anything else wrong with you and be mentally prepared for the trauma that comes with the surgery and recovery. Provided you aren't rejected, you move to Toronto to wait for the surgery and are started on an intense physiotherapy program. (Watson, 2019, p. 13)

This gamble of wondering whether or not your body is well or ill enough to then move forward with a transplant is also lacking a take on how many bodyminds (Schalk, 2018), are having to negotiate around systems of power on whether or not they are deemed worthy enough for life saving treatments. She is speaking mainly to the medical industrial complex's take on our bodies and making sure that there are no other concerns that may impose on our transplant however, I argue, if there are other oppressive societal states at play, this can impact our chances of survival, this illness is not simply a, medical problem, it is also a societal one.

Watson also writes about the decision to be put on anti-anxiety medications: "I understand why the majority of people listed for transplant are on anti-anxiety medication. The process causes a lot of stress" (Watson, 2019, p. 14). Needing medication to help deal with the magnitude of an operation that large is nothing to be ashamed of nor needing anti-anxiety medication all your life while having this condition. One area where this illness can feel daunting all our lives is in relation to being disabled and the demands of capitalism, leaving many people feeling useless and unproductive which can be wearing mentally, emotionally and physically on disabled bodies, making one feel incredibly disposable (Piepzna-Samarasinha, 2018). Many CFers take anti-anxiety medications in order to help deal with the constant daily life stressors that are placed on a disabled bodymind that somehow needs to find a way to

function in a capitalist, ableist world, not to mention the daily exhausting grind involved of surviving the full-time job of the illness itself with hours of treatments and so forth.

Subsequently, she discusses the first time she needs to be put on oxygen, noting, “I was self-conscious of wearing it in public, so while I would strap it on at home to lift weights or stretch, I did not like using it around other people” (Watson, 2019, p. 15). It is one thing to feel uncomfortable about having to wear oxygen tubes to help yourself breathe and showing it in public but at some point, you will either deteriorate completely or will be able to take them off due to doing better. Imagine having a skin tone that you cannot alter that brings with it societal stigmas and dangers, this is something that an intersectional perspective brings to the conversation to understand the power dynamics of body politics of someone with this illness and who is a POC.

*Transplanted* also touches on the mental health struggle of living with an *invisible* illness.

Watson discusses further:

As CF is a hidden disease, other people often have a hard time recognizing our level of illness. The downside to having a hidden disability is that people make assumptions about our abilities. Normally, that would be something I embrace, as people don't automatically assume limitations before getting to know me. (Watson, 2019, p. 18)

From an intersectional gaze, I argue that many things can be invisible when it comes to dealing with relations of power, hence why seeing more CFers write on more than this illness matters to help discuss those struggles of systemic oppressions that may not always be seen.

She addresses judgements from able-bodied folks while doing her best to push herself hard while in the rigorous physiotherapy program, she declares: “after each physio session, the

physiotherapists would review and sign cards, sometimes making notes or comments such as, “perhaps you need to increase your weights”, or “I think you should walk at a higher speed” (Watson, 2019, p. 40). Being able to read one another’s bodies on what it is capable of doing is important, having that sense of someone who is also struggling helps to dispel areas of tension around ableism (Piepzna-Samarasinha, 2018). This crip emotional intelligence helps foster better understanding around able performance of non-abled bodyminds. For example, two CFers may be able to have a great crip emotional intelligence rapport due to understanding those parameters around able-bodiedness and the ongoing limits or frustrations of their disability. This need to not always have to rely on having to explain to able bodied folks what is happening with their particular CF bodymind, is in a way a more relaxed and understood way of communicating those specific needs to one another.

*Transplanted* also covers the concern around socially/mentally not wanting to engage with others who have CF, Watson maintains, “I’m not sure if it’s an emotional survival mechanism (the more people you know with CF, the greater the odds are of watching them die) or if we’re just antisocial that way” (Watson, 2019, p. 45). It can be a delicate area of building friendships with other CFers, the inevitability of death is an ever-present haunting thought, however, the beauty and understanding that can also be explored together should be appreciated too. I maintain that intersectionality and specifically, disability justice in praxis, can help to make one feel like they are not alone in certain societal battles, that working on building coalition politics with other struggling groups can help people do more active care work to aid one another to survive (Piepzna-Samarasinha, 2018). This coalition building can help foster a more collective take and force against this illness.

Watson, post-op, has to endure embarrassing moments of losing control of her bowels/independence of using a bathroom: “let’s be honest, pooping is no joyride to begin with, but as I was being fed 100% liquid calories through my nasal tube, it was all just liquid out as well. And since all of my muscle control was gone, I had absolutely no bowel control” (Watson, 2019, p. 99). There are many times where we lose the ability to be independent and have needed to rely on someone else to perform a vital function for us. However, I argue that if we look at certain marginalized backgrounds, we can also see that many people who have CF and are disenfranchised, may feel more uncomfortable asking for help due to knowledge around historical group oppressions in terms of medicine. Samarasinha mentions that this fear of accessing care comes after years of abuse from institutional “care” to many (Piepzna-Samarasinha, 2018). If we were to have more literature on lived experiences of certain institutionalized care that has come up for a minority group who has CF, it would shed light on their voices.

Being able to regain the ability to speak is a huge accomplishment for Allison and can draw a strong parallel to overcoming systemic trauma in terms of intersectionality. She adds, “I hadn’t realized how hard it would be to talk again and how much my throat muscles would deteriorate after the transplant” (Watson, 2019, p. 125). I argue, from an intersectional metaphorical/symbolism sense, Watson being able to speak again after a transplant is akin to addressing oppressed groups who have had to find the courage to speak up over systemic traumas such as rape, racism, homophobia, sexism, transphobia, ableism, xenophobia and others.

She discusses the feeling of finally realizing that someone else’s lungs are keeping her alive: “Personally, I found the weirdest part about the whole experience was the ‘needing

someone else to die in order for me to live' part" (Watson, 2019, p. 156). This raises the point of whether or not someone who may be a POC will feel that they may be being forced to have to give up their independence from both CF and then needing help from the medical system. This uneasiness stemming directly from minority bodies being institutionalized because of past issues in care (Piepzna-Samarasinha, 2018). These failures are placed on people of colour to make it more problematic for someone to navigate accepting white donor lungs, possibly setting in motion an internal conflicting dialogue around feeling invaded, conquered and imperialized by a predominantly white medical system.

How post-op recovery is for Watson also brings up a valuable discussion on pushing yourself to the brink expecting major results: "as for me, however, it seemed like I was spending all my time sleeping and trying to walk up a single step. It was great that I could breathe easily, but was frustrated by my inability to do anything else" (Watson, 2019, p. 179). I think this can relate directly to what Samarasinha states in terms of being disabled but still actively addressing and taking part in activism, i.e "femme emotional" work (Piepzna-Samarasinha, 2018). During the age of Covid and the uprising of BLM protests, many people who have CF and POC, may feel that this type of activism is an accessible means to help make a difference in protests and other valuable causes. As Watson struggles to become more physically fit after post-op, intersectionality speaking, when the body feels heavily disabled, there are ways around being present in social movements where you can still feel like you are making a valuable difference. In terms of CF pre-transplant, this is also critical to think about if you struggle to feel like you want to belong in giving your voice to activism.

Furthermore, Watson is eventually with time and persistence, able to enjoy her physical activities again: “As cheesy as it sounds, I was so excited I could do all these activities again that being able to bike ten kilometers without much struggle was rewarding on its own” (Watson, 2019, p. 195). In a metaphorical sense, Watson being able to enjoy life again post obtaining new lungs, can relate to ways in which any oppressed individual can feel to finding ways to outsmart and navigate a system of oppression, to build resilience in a way that makes one feel that they have a chance at living a full life and being able to expertly engage with those societal power relations.

In *Transplanted*, the topic of immigration isn’t outwardly discussed. Watson is from New Brunswick and later settles in Springhill, N.S, Canada. There is no mention of any issues in regards to her having access to healthcare or any other struggles that immigrants may have to go through coming to Canada with cystic fibrosis. It would be a great access point if more immigrants were able to share their stories through literature or other creative avenues on some of the struggles they endure, specifically around undergoing a lung transplant. These stories might include things such as language barriers, cultural norms around medical procedures/medicines and other ethnic related trials and tribulations around navigating Canada’s healthcare system in relation to CF.

Watson expands on family/support and the relationship she has with her partner: “I think it helps that Isaiah knows where the boundaries are and when I actually need support. After so much time together and a lot of communication, we have a good system” (Watson, 2019, p. 216). Whether it is your relatives, partners or friends, when you have people around you who care



about you and will inevitably at one point or other, sometimes for years on end, take care of you, it is vital to know to never take advantage of that kindness. Being able to have open communication around able bodied/disabled concerns is crucial to help everyone in the relationship feel like they are contributing to a cohesive sense of well-being. Dating in general while having CF can be difficult. As CF does not allow people with the illness to date, it can be arduous at times to explain and make yourself vulnerable to letting people love you. Particularly if it revolves around the inevitable discussion of dying from the illness. From an intersectional perspective, many things can come up such as interracial tensions while being disabled, queer/gender conflicts/tensions, class oppressions, immigrant status and others that can have an impact surrounding vital care in relation to family/support networks that may have to be addressed and taken into consideration.

*Transplanted* mentions a little bit about finding safe housing in Toronto but does not go into heavy details, she covers the basics: “once we narrowed down our selection to a few areas of the city that were on a transit route, fit our budget, and all our (my) demands, the decision seemed less insurmountable. We wanted a furnished place, no basements, (due to the risk of mould), no mice or bedbugs, (because, obviously), no carpeting or smoking, and ideally with parking” (Watson, 2019, p. 29). Housing can be problematic for someone with CF, from class struggles that impact a safer/cleaner apartment, to advocating for yourself when dealing with landlords/rental companies and the risk of dust build up, i.e mould and harmful bacteria that can live in dust along with overall health impacts of dust itself. Consequently, this dust being anywhere from carpets to inadequate ventilation systems. In terms of disability and housing, addressing these intersectional concerns can save lives in the long term.

Watson's story does not cover insurance concerns which is problematic as I noted earlier in the analysis of the CF Canada webpage and the film, *Five Feet Apart* (2019), insurance has a direct impact on people's lives with this disease. It would be good to see others with CF with varied backgrounds, speak to lived experiences of undergoing a lung transplant and needing to deal with the anxieties around insurance while undergoing this procedure.

The one area of gender that she does mention has to do with when she ends up having cancer and has to go through chemotherapy. Watson remarks, "it's odd that at a time when I could not have felt less feminine, I experimented more with make up and earrings than I ever had before" (Watson, 2019, p. 211). She eventually was able to grow back her hair over time. This is a separate health issue she has to deal with due to having been diagnosed with cancer post-transplant but it does impact Watson's take on being gendered. Through an intersectional gaze, Lorde addresses the concerns around having cancer and the feelings around losing a body part that has been gendered i.e., her breast. She felt immense pressure to accommodate a medical/capitalist system more so than her own needs, being pushed into having a prosthesis (Lorde, 1980). Watson was able to over time regain her hair growth but Lorde was not able to regain her original breast. In terms of gender formation, for Watson, her hair coming back gave her the option to either accept short or long hair but where Lorde has lost a body piece permanently, even though she can choose to accept prosthesis, it is still not a full part of her own body. Even then Lorde was made to feel like she, "had" to take on a fake breast to be seen as more "womanly". *Transplanted* does allow for a conversation around an experience of undergoing a double lung transplant but does not encompass everyone's lived reality of this procedure.



## **CHAPTER 5: LORDE'S CANCER JOURNALS AS EXPLORATION OF ILLNESS/QUEERNESS/DISABILITY & BLACKNESS**

Audre Lorde is someone who notably centers her writing around being a Black, queer, disabled and a terminally ill woman. She uses a style of writing that brings her academic voice and her personal voice together. It is a unique method that allows her as a Black woman to bring forward personal experiences to help articulate system frustrations. I use an example of intersectional autoethnography through Alicia Griffin's concept of Black Feminist Autoethnography (BFA). I also utilize work done by Moya Bailey and Izetta Mobley around Black Feminist Disability (BFD) work to help broaden an intersectional understanding around Black Studies and Disability Studies. In this chapter, I argue that Lorde's *Cancer Journals* can be read as an example of an autoethnographic reflection on intersectionality and illness. I also draw on Bridget Minamore's work on Lorde's poetry as autoethnography. She uses poetry as a means to express complex personal experiences and observations through her battle with having a mastectomy. She is a prime example of what the CF community can learn from in terms of representation and thinking through Black people's experiences with medicine.

## **Autoethnography As Methodology**

Autoethnography is a methodology in which a researcher centers and reflects on their own lived experiences as part of their research. It looks at positionality and reflexivity as a means to analyze and discuss people's lives as knowledge building, thus aiding in epistemological frameworks for scholarly projects, activism, policy changes, and so on. This analysis of lived experiences is usually done through different lenses/analytical tools of thinking, such as intersectional feminism.

In particular, Rachel Alicia Griffin speaks to women of colour who have used a specific type of autoethnography called, "Black Feminist Autoethnography" to help discuss their lived experiences. In an article called, "I AM an Angry Black Woman: Black Feminist Autoethnography, Voice and Resistance," she articulates BFA:

To do so, I first address the invisibility of Black women in the field of communication and the larger academy. Then, I chronologically process through my personal introduction to Black feminist thought to position Black feminist scholarship in conversation with autoethnography. Connecting the two leads to a discussion of Black feminist autoethnography (BFA), followed by my use of anger to fuel my Black feminist autoethnographic reflections. (Griffin, 2012, p. 139)

Griffin helps us see that autoethnography can be a means by women who feel marginalized, have an opportunity to lend a personal voice to their experiences while dealing with societal oppressions. She elaborates on this point: "Nevertheless, I am optimistic in believing if I step into the space that resistant cries have created, maybe, just maybe, something about my resistant voice in this moment will be heard, taken in, and taken seriously. Maybe." (Griffin, 2012, p.

139). This need for her voice to be heard really anchors the importance around BFA. Griffin also writes about the realization that through reading other Black women of colour, i.e Collins, Hooks, Lorde, etc, that she too, was able to find a place called “homeplace.” This space allowed her to let her anger and voice be heard, particularly around being a biracial woman who always seemed to be an “outsider within” and an “Insider outsider” for so long (Griffin, 2012). For her, being able to access previous women of colour’s work has helped her feel she has a right to her anger about the injustices to her and people like her.

Autoethnography is a key component to helping marginalized groups speak to barriers and limits in society based around their positionalities around power relations. Griffin brings into focus the ways in which the anger ostracized groups feel is valid and its need to be respected and understood. BFA is a strong and resilient form of autoethnography that lets Black women explore a means to speak out on crucial points through their own lived experiences. I assert that this type of method allows for a sense of community/knowledge building and is an important way that Audre Lorde speaks to her fight around being Black, queer, disabled and having an illness.

### ***The Cancer Journals***

In, *The Cancer Journals*, Lorde depicts her journey of having breast cancer while navigating the body politics of being Black, queer, disabled and being terminal. Lending her voice to the conversation around medicine and Blackness is a direct link to engaging in Black

Feminist Autoethnography (BFA). She speaks to the problem that faces many women (sometimes men too) on the melancholy of wanting to go back, she states:

After a mastectomy, for many women including myself, there is a feeling of wanting to go back, of not wanting to persevere through this experience to whatever enlightenment might be at the core of it. And it is this feeling, this nostalgia, which is encouraged by most of the post-surgical counseling for women with breast cancer. (Lorde, 1980, p. 55)

In Western society, women's bodies have been utilized for generations to always include objectifying the breast, due to rigid gender norms and patriarchal narratives, our bodies have become an aesthetic concern. Cancer is something that ravages any part of the body and can account for many amputations and so forth, various ones that have to do more for valid bodily functioning than just a societal eye candy. Lorde goes on to make this point abundantly clear emphasizing:

As a 44-year-old Black Lesbian Feminist, I knew there were very few role models around for me in this situation, but my primary concerns two days after mastectomy were hardly about what man I could capture in the future, whether or not my old boyfriend would still find me attractive enough, and even less about whether my two children would be embarrassed by me around their friends. (Lorde, 1980, p. 56)

A Black Feminist Disability (BFD), framework can address here the issues many Black and disabled people will face in relationship to ableism within their own communities (Bailey & Mobley, 2018). Lorde did not have role models at that time to look up to or relate to in terms of her lived experience. This makes her work even more so important in our current day times around dealing with oppressions within the medical setting.

Cancer societies need to make certain that their priorities are set appropriately, make cancer survivable, not pretty. She goes on to speak on the point of making it through your life once you know you are dealing with such an aggressive and sometimes quick illness and being surrounded by women:

A lifetime of loving women has taught me that when women love each other, physical changes do not alter that love. It did not occur to me that anyone who really loved me would love me any less because I had one breast instead of two, although it did occur to me to wonder if they would be able to love and deal with the new me. So many concerns were quite different from those spoken to by the Reach For Recovery volunteer, but not one bit less crucial nor less poignant. (Lorde, 1980, p. 56)

The true test is not whether your partner, family, friends, colleagues, and so on are able to get used to the fact that your breast(s) may be gone but that an old part of your emotionally, mentally, spiritually may be gone as well. Cancer as we know today, takes much more from us than just our body parts, organs and so forth. Now imagine being Black and disabled. How race and disability impact one another is a hallmark of BFD, which shows the compounding effects of those two marginalized societal categories can impact people and their lived experiences (Bailey & Mobley, 2018). Lorde didn't just face an illness but she also faced ableism and racialization, all of these aspects were not fully spoken of or thought about from the Reach for Recovery group.

Lorde reflects on the real matter at hand, how can terminal illness make you more aware of your life:

I am talking here about the need for every woman to live a considered life. The necessity for that consideration grows and deepens as one faces directly one's own mortality and death. Self scrutiny and an evaluation of our lives, while painful, can be rewarding and strengthening journeys toward a deeper self. For as we open ourselves more and more to the genuine conditions of our lives, women become less and less willing to tolerate those conditions unaltered, or to passively accept external and destructive controls over our lives and our identities. (Lorde, 1980, pp. 57-58)

Living with a terminal illness can hamper how we live our lives, or it can help us see things differently, on a larger, more appreciative scale. In relation to BFD, Lorde's thoughts on women who are faced with cancer may think differently around conditions in their lives for which they no longer will stand for. One such area is ableism and the workforce (Bailey & Mobley, 2018).



Living a considered life by being confronted with cancer, can help address some of the ways in which women's lives have been held back by marginalization perhaps, how women are treated in an ableist workforce is just one area that needs consideration. For some, using the written word can help to bring a more considered life forward. Lorde does this with poetry, particularly being able to bring action into play around using the written and spoken word. She does so by helping bring an intersectional take on living by her words that eventually became a form of activism (Minamore, 2018). For many people, activism is done through narratives such as Lorde's life experiences.

Lorde reminds us that her work and her very life, became a journey of experiences that helped shape her activism and poetry. Minamore elaborates on the following:

Her writing always speaks from the core of her being, and it is part history, part protest. The prose that emerges from this place snaps and crackles, and every other sentence feels quotable" every black woman in America lives her life somewhere along a wide curve of ancient and unexpressed angers"; there are no new ideas. There are only new ways of making them felt. (Minamore, 2018)

That lived history is what became the current and future aspects of her activism and protest against oppressions in the world of medicine with the positionality of her bodymind.

In an incident where she had to have her stitches taken out, the inevitable push toward prosthesis was made. Lorde says:

Here we were, in the offices of one of the top breast cancer surgeons in New York City. Every woman there either had a breast removed, might have to have a breast removed, or was afraid of having to have a breast removed. And every woman there could have used a reminder that having one breast did not mean her life was over, nor that she was less of a woman, nor that she was condemned to the use of a placebo in order to feel good about herself and the way she looked. (Lorde, 1980, p. 59)

Garland-Thomson helps us navigate this as there is an ongoing concern around reconstructive surgery, where it eliminates disability and places emphasis on what "normal" should look like.

Reconstructive and cosmetic surgeries capitalize off the body and bring a sense of misaligned well-being (Garland-Thomson, 2002). Instead of embracing the difference, it is obvious that medicine/larger societal gender norms try to “correct” the disability. BFD explores further the problematic connection of disability and eugenics thinking that is pervasive in the medical world. Many of those women may feel “unfit” as people in society, which relates to the social and medical models of disability (Bailey & Mobley, 2018). The medical model is prevalent in wanting to “fix” an individual, but the social model sees disability as a larger problem within society.

Lorde also touches on the extreme importance of being seen as a warrior against cancer, that women who have scars from this insidious monster are to remember that those scars are to be looked at as being a survivor, Lorde views:

I have been to war, and still am. So has every woman who has had one or both breasts amputated because of the cancer that is becoming the primary physical scourge of our time...For me, my scars are an honorable reminder that I may be a casualty in the cosmetic war against radiation, animal fat, air pollution, McDonald’s hamburgers and Red Dye No.2, but the fight is still going on, and I am still a part of it. (Lorde, 1980, p. 60)

BFD speaks to this myth that Black women have always had to be seen as “strong” women, which is dismissing the very real lived realities of Black women who are disabled (Bailey & Mobley, 2018). Lorde explores how she feels that the scars of cancer show her successfully combating it but is also aware that there is a larger battle taking place within society against the disease. She acknowledges this ongoing fight with determined strength, but it is also seen the continued trope put on her to “have” to be strong as a racialized Black woman.

Minamore helps us see how Lorde’s life became an activist piece itself, that the poetic prose that emerged from her experiences help dictate how she is seen as a strong front against cancer and

being a Black woman, (Minamore, 2018). Lorde lived against a system that was set in place to oppress her, from her health, to her race, to her sexuality, her ability, and her womanhood.

She mentions the grave dangers of keeping silent when it comes to surviving things such as breast cancer, that all women have voices and the voices matter greatly to help build a more collective idea around our battle with illness, noting:

If we are to translate the silence surrounding breast cancer into language and action against this scourge, then the first step is that women with mastectomies must become visible to each other. For silence and invisibility go hand in hand with powerlessness. By accepting the mask of prosthesis, one-breasted women proclaim themselves as insufficiently dependent upon pretense. We reinforce our own isolation and invisibility from each other, as well as the false complacency of a society which would rather not face the results of its own insanities. (Lorde, 1980, p. 61)

Lorde speaks directly to BFA by acknowledging the concern around women remaining silent on how illness affects the body, a fact that Griffin has also brought up as well (Griffin, 2012). Both Lorde and Griffin address the need for Black women to speak up about their experiences and that their voices are not a passive voice. Minamore also addresses this concern while studying Lorde's work, particularly the importance of speaking up, that differences are not what keep us apart but silence (Minamore, 2018). This, I argue, helps the conversation around Lorde's narrative of "sisterhood" within feminism, the constant strife of what constitutes "feminist" thinking. Garland-Thomson helps along with that narrative by stating the important merger of disability and feminism (Garland-Thomson, 2002). One can simply not study feminist ideals without including disability narratives for a more intersectional take on people's lived experiences.

Lorde takes it further by focusing on the fact that there is the inevitable increase of breast cancers:

As women, we cannot afford to look the other way, nor to consider the coincidence of breast cancer as a private nor secret personal problem. It is no secret that breast cancer is on the increase among women in America. According to the American Cancer Society's own statistics on breast cancer survival, of the women stricken, only 50% are still alive after three years. This figure drops to 30% if you are poor, or Black or in any other way part of the underside of this society. (Lorde, 1980, pp. 61-62)

Lorde shows that if you are disenfranchised in the system, cancer survival rates are greatly impacted. There is an ongoing narrative around the privilege of cancer survival, hence why it is crucial that cancer research gets looked at with an intersectional feminist lens to help save women's lives, an ongoing argument in this thesis: that race, and medicine are closely related to health outcomes. Lorde addresses here the complex nature of the medical and social models used in medicine around disability, particularly where she is aware of the problems caused by society that leads to cancer proliferation and that it is not just an, "individual" problem but a larger structural concern to marginalized people's health and who gets accessibility to medicine. (Bailey & Mobley, 2018). This disenfranchisement of racialized, poor and female bodies against how cancer is fought is a hallmark of Lorde's written work, speaking up for those who are already struggling to survive in the first place and how inaccessible the medical system is.

Lorde explains this dressing up of the female body as a capitalistic venture that needs to stop taking place:

We are surrounded by media images portraying women as essentially decorative machines of consumer function, constantly doing battle with rampant decay. (Take your vitamins every day and he *might* keep you, if you don't forget to whiten your teeth, cover up your smells, color your grey hair and iron out your wrinkles.....) As women, we fight this depersonalization every day, this pressure toward the conversion of one's own self-image into media expectation of what might satisfy male demand. (Lorde, 1980, p. 64)

Lorde brings into focus some of the ways in which women's bodies have become capitalist ventures and how this has a long-standing history in relation to racialized Black bodies and the need to constantly produce work for profit (Bailey & Mobley, 2018). Not only were oppressed bodies used for work but then they became items of profit based off of consumer male demand. Garland-Thomson notes the same and credits Lorde's work on cancer, feminism and the body in relation to her title of "politics of prosthesis" (Garland-Thomson, 2002). Going along with the patriarchy for the sake of one's own health is detrimental and needs to be continued to be dismantled for the safety of women's health everywhere. Navigating through oppressions and privileges is time consuming and demanding, she reports:

As women we have been taught to respond with a guilty twitch at any mention of the particulars of our own oppression, as if we are ultimately guilty of whatever has been done to us. The rape victim is accused of enticing the rapist. The battered wife is accused of having angered her husband. A mastectomy is not a guilty act that must be hidden in order for me to regain acceptance or protect the sensibilities of others. Pretense has never brought about lasting change or progress. (Lorde, 1980, p. 65)

An illness/disability should never be seen as something that you need to feel guilty about because it may take away a "gender norm" in society. Here is a way that the intersections of gender and health intersect. Lorde reminds us to live a more lasting message that speaks to our bodyminds, that our oppressions do not make us any less worthy of basic human rights, compassion, respect and dignity. Particularly, if you are someone who identifies as both Black and disabled, this guilt needs to be addressed within Black communities as there is still an ongoing feeling of shame around not being able bodied or white due to the "twice as good" mentality around survival within these communities (Bailey & Mobley, 2018). If you grow up Black, you are told that in order to survive racism, classism and ableism, to behave in a way that

placates white ideals. We have seen numerous times, particularly in the wake of Black Lives Matter movements, that the “twice as good” narrative does not work against this system.

Lorde also recognizes the critical importance of seeing through the lies and deception that most cancer societies seek:

The mortality for breast cancer treated by conventional therapies has not decreased in over 40 years. The American Cancer Society (ACS), and its governmental partner, the National Cancer Institute, have been notoriously indifferent, if not hostile, to the idea of general environmental causes of cancer and the need for regulation and prevention. (Lorde, 1980, p. 72)

Here is a direct way that Lorde uses her cancer experience as a means to direct words into action by discussing the issues she sees around how cancer is being viewed and its harms to society, again, her way of being an activist.

### **Poetry As Method**

When trauma or societal frustrations occur, the mind tries to understand and cope with the fallout from those lived experiences. Many people turn to creative painting, music, or other artistic outlets to try and deal with past memories and emotions. Engaging in poetry can be a means of taking an active resistance to a system of oppression by bringing into focus words and context of lived experiences, aiding to bring forth a means of activism or a call to action. It is also a research tool that is knowledge building, helping build epistemology for both the academy and the wider public at large. Through the positionality of the writer, i.e., being aware of their own privileges/oppressions, it helps them to situate themselves within their own work.

Moreover, being reflexive of poetry is key to knowing you took the time to examine lived experiences and learn from your past and how it may help others.

Lorde has made it clear that the use of words can have powerful results for action which has fueled my need to speak to her experience of navigating a terminal illness with her unique positionalities. In a review by Bridget Minamore called, Audre Lorde's "Your Silence Will Not Protect You", Minamore shows us the ways in which Lorde used her poetry to convey her earnest, poignant struggles in her life, especially around illness narrative, Minamore notes:

Throughout her essays Lorde reiterates the importance of language and, above all, the importance of shifting language into action. Her poetry is a powerful example of that shift in action. By providing both more or less-deeper, more direct meaning in fewer words-her poetry is able to articulate the complexities of women's pain and enact in her reader the empathy and movement to action she calls in her prose. (Minamore, 2018)

Lorde's way of using language that also became action, is remarkable. Minamore continues as she discusses the importance of how Lorde brought into focus the contrasting struggles being faced by women who were not white, middle class, heteronormative, she continues:

"The Transformation of Silence into Language and Action", lays out themes that recur throughout the book. Lorde writes of silence versus speaking up, fear versus bravery, feminist division versus sisterhood, and the way these opposites often go hand in hand. Each of these supposed negatives-silence, fear, division-can and must, she argues, be transformed into corresponding "positive". (Minamore, 2018)

Lorde is specifically using poetry as a means to bring forth the urgency on women speaking up about their struggles, battles and injustices done to them.

Lorde speaks further of this "division" within feminism and its connection to sisterhood. Lorde was a huge proponent of speaking out over feminism that neglected the voices of disenfranchised women, Minamore comments: "What is most important 'must be spoken', she writes, over and over, if we are to have any positive change. "The Transformation of Silence into Language and Action" ends with: The fact we are here and that I speak these words is an attempt to break that silence and bridge some of the differences between us, for it is not

difference which immobilises us, but silence” (Minamore, 2018). This is a critical point of Lorde’s, differences should be voiced, not kept in the dark.

Lorde reminds us that her work and her very life, became a journey of experiences that helped shape her activism and poetry. Minamore elaborates on the following:

Her writing always speaks from the core of her being, and it is part history, part protest. The prose that emerges from this place snaps and crackles, and every other sentence feels quotable”every black woman in America lives her life somewhere along a wide curve of ancient and unexpressed angers”; there are no new ideas. There are only new ways of making them felt. (Minamore, 2018)

It is clear that her very life became an act of rebellion against the status quo and societal oppressions, especially in relation to the world of medicine.

Minamore states that Lorde’s writings are a key to looking at the past in order to help address future problems: “While so much feminist thought is preoccupied with the solutions of the future, Lorde’s writing is arguably at its most radical when it looks to the past to solve our problems” (Minamore, 2018). Lorde addresses how activism through speaking up is important to drawing attention to age old closed off and dangerous narratives. There have been many people who have utilized poetry in order to show their frustrations with the ongoing and current system. There is something extra powerful about using poetry, it is not just the words, but the delivery of those words that can truly matter. Poetry can be seen as a performative piece, when one stands in front of a crowd, one conveys our real time emotions to those words. How we speak the words, how we feel the words all matter for a successful deliverance of urgent social calls for change. Some of us use metaphors in our words, some use telling titles, others compare struggles and others are waiting to perform their pieces to help make it more real.



## Epigraph Analysis

Audre Lorde's poem "After Images" is a profound piece of written poetry that brings into focus the ways in which Lorde sees the constant brutality against Black bodies, hers included. She specifically draws on the events surrounding Emmett Till and reflects on how she understands this pain. Imagery is noted a great deal, both in terms of "sight", seeing the aftermath of a broken, violated Black body done by a white, racist system and the "site" of this violence, the everyday dealings of American society and its relation to inflicting Black pain onto communities. It also reflects how Lorde sees this boy's murder as a means to draw a parallel of "insight" towards the inner and outer pain that she endured while having cancer, being a woman, queer and Black while having the medical world inflict pain upon her.

...Within my eyes  
 the flickering afterimages of a nightmare rain  
 a woman wrings her hands  
 beneath the weight of agonies remembered  
 I wade through summer ghosts  
 betrayed by vision  
 hers and my own  
 becoming dragonfish to survive  
 the horrors we are living  
 with tortured lungs  
 adapting to breathe blood.  
 (*After Images*, Lorde, 1997).

Working with poetry and ethnography as methods of self-exploration, I composed five prose-poetry stanzas exploring individual lines from *After Images* from my own perspective.

After images of a nightmare rain, reminds us of nights when CF would try and suffocate our airways, the trauma incurred by repeated, “nightmare rains”. Women with CF die sooner so our worries are multiplied, wringing our hands. “Weight” is a trigger word for us, our agonies of feeding tubes/weight concerns remembered. We wade through Summer ghosts, of admissions, clinics and Cfers lost, water reminding us of the obstruction of our lungs, how little air seems to pass through them. Summers are hard, when we should be out enjoying ourselves, we are indoors doing treatment after treatment or trying to fight heat exhaustion, or keep our sodium levels up, or dealing with stifling humidity. Summer is not always green, sunny and happy for us. Sometimes, our vision goes with CF, sometimes the lies they tell us of a cure around the corner feels like a betrayal, the vision of a cure for all still not fully in reach. Hers and my own, a mother who has a child with CF is betrayed by the future visions around a cure, vice versa, a mother who has CF is dismayed by the future vision of not having time with her daughter. Two sisters with CF struggling to see the future together, two friends with CF etc. One must become a fish to survive in water, we are trapped in a sea of terminal horrors and obligations and responsibilities. The metaphor of the fish, the deeper it goes in the ocean, the harder it becomes to breathe, the pressures of the water and darkness remind us of the struggles of daily life with our lungs. When a fish dies on land, it is gasping for air, the symbolism of the fish to the reality of CF is blatant, the horrors we are living being terminal. With our tortured transplanted lungs, we fight with bleeding in our airways, attempting to adapt to fight for our lives.

A Black woman, standing in a rainstorm, the taking of her people’s freedoms, being dragged onto a transatlantic slave ship. Our eyes capture moments of our lives, part of having a lived experience. She is wringing her hands as we move forward to the night a Black woman wakes to seeing a burning cross on her lawn, the agonies of her people remembered, the weight of the shackles. We hear the voice of MLKJr. telling us we must rise to the mountaintop for his dream, civil rights horrors with the water from a hose. In the Summers, we waded through thick, suffocating fields of cotton, remembering those who died with us on our journeys overseas. We are betrayed by visions of freedom, it is 2021 and our skin has had to morph into fish scales in order to be able to swim and adapt to the oceans of injustices and prejudices. “We can’t breathe”, the cops who kneeled and gunned us down. Under this horror of our tortured, bloody lungs as Emmitt Till and George Floyd died.

Flickering after images of a night time gay bar raid, a mother wringing her hands waiting for word of the safety of her child. Beneath the weight of agonies remembered of Stonewall and political diminishing of Trans rights. As Summer Pride parades go on, we are surrounded by the ghosts of those who just wanted to love and are tragically gone. My partner and I are betrayed by visions of equity around our love. We swim to the depths of the oceans as fish to get away from the glare of a cruel, homophobic/transphobic society. In our quest for sex reassignment surgeries, we breathe the blood and pain that comes with wanting to feel accepted.

A night in the rain, waiting by the border, will they let us in? A nightmare of trying to gain access to new sought after lives. The after images of the trauma of being told to go back to where we came from, the xenophobia raw. A woman wrings her hands, will her family be safe finally? Will the persecution stop? Beneath the weight of agonies remembered in a land she no longer feels safe in, one she desperately is trying to flee. She wades through Summer ghosts of gathering her family's belongings, preparing for a perilous journey into foreign lands. The vision of a better future is within her reach, her daughter's, her sister's, her grandmother's, her mother's, her own. Hoping for no betrayal of freedom by bureaucrats, red tape or silence or inaction. In a sea of millions of people, only a few are able to leave and start anew. The horrors she has been living, in this war, over years of having had to adapt to breathe the blood of it's crumbling society.

Standing outside in the rain, realizing the nightmares of being homeless. Struggling to make ends meet, a woman wrings her hands, will we have enough to eat? Beneath the weight of agonies remembered, the tax collectors, the debtors, the landlords, the banks. Wading through Summer ghosts, when the chill of the Winter isn't as harsh to survive in. Betrayed by vision loss, can't afford a doctor. Becoming marine stock that is overfished, our supplies dwindling, the class struggle, will we survive? The horrors we are living, to just make it in the system. The homeless man on the street, whose lungs are filled with blood, cuts deep.

Above, I draw upon this one specific stanza and analyze it through an intersectional feminist framework and write four specific ways in which those particular lines remind me of lived experiences around disability, race, gender and sexuality, ethnicity and class that relate

strongly back to my research project. Those specific lines draw upon both separate and compounding effects of marginalization that I relate to through the written work of one of my key theorists. I use the words, “us/we” on purpose as I feel strongly connected to many disenfranchised groups and felt compelled to speak up for many communities through this analysis. I also wrote each section as its own poetic piece that had an intricate integration of Lorde’s work allowing for my own metaphorical imagery and symbolism to show the struggles of these societal oppressions. In order to achieve an accessible imagined society/future where marginalized communities’ needs are met, society as a whole needs to be comfortable seeing these, “after images” of systemic trauma and acknowledge that change needs to take place.

## **CHAPTER 6: CONCLUSION**

In summation of this project, I would like to draw upon some of its findings to help evaluate some of the sociological representation of this illness. In my literature review I spoke to specific medical research that highlighted Black populations with this condition, race correction that was done to the Black community in regards to spirometry outcomes and Black pain tolerance in the medical field. Mentioning personal stories of Black folks and the trans community regarding people who have CF helped to bring into focus the need for personal voices. This thesis also demonstrated the need for more representation in medical trials and allowing minority groups to partake in them. I wrapped up my literature review looking at Parsons's "Sick Role" theory that was shown as problematic to permanently ill/disabled bodies through Lorde's critique of it. I also set the stage for bringing in intersectional theory and some of the main theorists that draw on this analytical tool, such as Kimberlé Crenshaw, Patricia Hill Collins and Sirma Bilge.

Through theory and method, I explored the importance and relevance of intersectional thinking that was presented by Kimberlé Crenshaw and further expanded on by Patricia Hill Collins and Sirma Bilge. I brought in work by Sami Schalk who relayed importance of literary representation around race and Disability Studies and Alison Kafer who helped me discuss a more broadening layer of intersectionality through queer crip. Rosmarie Garland-Thomson's work helped me to understand the importance of feminist disability studies. Nirmala Erevelles helped me bring in CRT and Disability Studies. Leah Lakshmi Piepzna-Samarasinha helped me argue the ways in which we can practically utilize intersectionality through Disability Justice work. For methodology, I centered marginalized voices and actively questioned their lack of

representation, all while utilizing an intersectional approach to help critique their lack of presence in research. For methods, I drew from three disciplines of content analysis(sociology), media analysis (cultural/communication studies), and literary analysis(literature). Those questions were based around an intersectional theoretical and disability justice framework. The particular questions used helped me analyze a webpage, a film and a memoir and were focused on race, class, gender, sexuality and disability/illness. This analysis brought out many areas lacking an intersectional feminist narrative around this disease.

The use of autoethnography helped to see the importance of lived experiences. Audre Lorde's *The Cancer Journals*, aided to see the kind of self-representational voices we need in the CF community based on looking at her experiences of illness/queerness/disability & Blackness.

### **Limitations**

My one area of limitation with this project was that I did not draw upon the wider CF community such as having been able to acquire lived intersectional experiences of race, class, gender, sexuality and disability/illness through interviews, case studies, participatory action research, (PAR) and other methods to help frame my knowledge building around this illness.

### **Contributions**

I have argued that representations of cystic fibrosis in media, literature and popular culture lacked a more complex understanding of the positionalities of people's lived experiences of CF. I think this is a major contribution to the wider CF community as it helps bring

marginalized voices of this illness to the forefront. By allowing more critical and diverse stories to come forward, it will help pave the way for more precedent research on medical guidelines, government policy changes, legal frameworks, social programming, accessibility to healthcare and other much needed aids to help combat this illness as a holistic approach. Moreover, as separate projects featuring CF, the webpage, the film and the memoir offered some insights into life with this illness, but there is yet to be a single project that is a total encompassing take on living with it, i.e modulator access, six foot germ protocol and transplant to name just a few. A true representation of it would be to discuss those avenues all at once and include an intersectional take on those lived experiences which I hope is a conversation this thesis can produce.

### **Future Research**

A unique way to move forward is through an emerging new form of treatments that are gene therapy based. One called MRT5005 and the other known as CRISPR/Cas9. MRT5005 has the opportunity to help fix the dysfunctional CFTR protein, which would help eradicate the illness (Carvalho, 2019) and CRISPR/Cas9 looking at using the body's own DNA repair mechanism system. My thesis articulated that the compounding of oppression states of race, class, gender, sexuality, disability/illness around cystic fibrosis, with this new treatment on the horizon, it could take away one marginalized marker around illness. Other power relational states may remain in an individual even after they may be cured from this condition but it is a starting point in terms of science meeting society. Carvalho speaks to the fact that even patients who are not on a CF modulator, are going to be able to benefit from this scientific potential: "among the 12 participants in the first part of RESTORE-CF, 11 had at least one copy of the

F508 deletion, the most common CFTR mutation associated with the disease. One person did not carry any copy of the F508 deletion and was not eligible for treatment with the CFTR modulators. Seven of the 12 participants were being treated with an approved CFTR modulator during the study” (Carvalho, 2019). Research like this will hopefully see the beginning workings of a cure for all.

Gene therapy is a means to tackling this illness and potentially providing a more inclusive cure as it does not rely on research only looking at specific genetic codes such as the research predominantly behind current day modulators. The research known as CRISPR/Cas9 is looking at specific gene editing that can take place within the body. The following explains scientifically how this process takes place:

The CRISPR gene editing tools include a “guide” that locates the mutated sequence of the CFTR gene, a template with the correct segment of DNA letters, and “scissors” that break the patient’s DNA at the site of the mutation. Once the tools enter the cell and reach the mutated sequence DNA, the scissors snip out the mutation. This damage attracts the attention of the cell’s DNA repair machinery, which will then use the template to fix the break in the DNA. This permanently corrects the mutation in that cell. This gene editing process can repair one mutation at a time, or groups of similar mutations, depending on how the mutations are arranged in the DNA. (Cystic Fibrosis Foundation, 2019)

This innovative research has the potential to help stop this illness by using the body’s own repair system. One major drawback is the risk of snipping out the wrong DNA sequence which could cause problems such as cancer to form. As well, it needs to be delivered to specific areas of the body that need fixing. Thus, where a majority of the damage done by CF is in the airways, gene therapy has had a difficult time getting the lungs to accept this kind of treatment. It has been picking up speed in the last few years and is continuing to make strides to help successfully rid



the human body of this faulty gene. Both these methods of gene therapy help further my argument around representation and combating Cystic Fibrosis.

In relation to Cystic Fibrosis and the sociological framing of this illness, this thesis has helped demonstrate some of the ways in which a more inclusive response can be enacted in order to help anyone who is marginalized in the CF community feel represented. Intersectional feminist thinking around CF can ultimately help save lives.



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