

**Feminist Phenomenologies of Illness**

by

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This thesis was prepared under the direction of the candidate's thesis advisor, Dr. Nicole Morse, Department of Women, Gender, and Sexuality Studies, and has been approved by all members of the supervisory committee. It was submitted to the faculty of the College of Arts and Letters and was accepted in partial fulfillment of the requirements for the degree of Master of Arts.

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## **Abstract**

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The experiences of those with difficult to diagnose conditions, chronic illnesses, and disability lack intelligibility in an able-bodied world. Much of this originates in the disjuncture between first- and third- person experience as accounted for between patients and their doctors, caregivers, and the greater public. Utilizing the insights of feminist philosophy and disability studies, I will explore how these marginalized identities face consequences in the real world for their embodiment.

I propose that the best methodology to examine the experiences of chronically ill, hard to diagnose, and disabled individuals' experiences is through the phenomenological perspective. Through utilizing case studies, I will demonstrate the importance of first- to third- person encounters in medicine and receiving adequate treatment. By examining such experiences, as well as my own, through such a perspective, I argue we can work towards creating a more equitable world for the chronically ill, hard to diagnose, and disabled.

## **Dedication**

I would like to dedicate this project to my mother and father, who have always supported and believed in me. Without all their love and care over the years, I do not know where I would be. You have always supported my ideas, even if I was talking about a subject matter that you knew nothing or a little bit about. I hope that this work helps to demonstrate those ideas more clearly. I love you.

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## Introduction

There is a massive gap in the understanding of people with hard-to-diagnose conditions and invisible illness within the realm of collective intelligibility. The public imaginary of the disabled body generally submits to a single criterion: a disability *that is easily read to the able-bodied public*, such as an impairment that restricts an individual to a relying on a wheelchair, a blind-person with a trusted companion, or a the deaf-individual participating in a social situation. These examples of socially recognized disabilities bring to question, what *is* disability? How do we, as a society, perceive and evaluate the disabled body? What qualifies as disability, and who makes this determination? At the heart of these questions is the issue of intelligibility and comprehensibility – how the disabled/chronically ill communities are perceived by and interacted with by the able-bodied majority.

Disability studies attempts to provide answers to such questions. Making the crucial differentiation between impairment, the bodily states and/or conditions taken to be impaired, as defined by medical norms and expectations, and disability, the social process of disablement which gives both meaning and consequence to impairments in the world rather than referring to bodily states, disability studies analyzes the lived experiences of disabled people and the challenges they face based upon their embodiment within an ableist culture. Such focus has illuminated the ways in which compulsory able-bodiedness frames the environments we live in, the institutional structures that shape our



lives, and the society that we are able (or not) to participate in. However, disability studies, particularly within the humanities, has frequently focused on visible physical and sensory impairments, with less attention paid to intellectual and psychiatric impairment. Even less attention has been paid to those who fall into the perceived gray areas of disability: the hard-to diagnose and those chronically ill with invisible impairments. As such, my primary focus will be on these conditions as physical impairments rather than attempting to testify to the experiences of those with cognitive disabilities, or all disabilities generally.<sup>1</sup> But this begs the question: what makes a disability intelligible to the disabled community, or the world at-large?<sup>2</sup>

This project serves multiple goals: to elucidate the disjuncture between lived experience and perceptions of well-being, to question the connections between disability categorically and bias in medicine, and to bring to light the experience of those who are caught in the crosshairs. Such work is informed, and inspired, by my own experience of living with a difficult-to-diagnose genetic condition. Over the course of a decade, I existed within diagnostic limbo: I was too young to be experiencing the symptoms I claimed to be experiencing, while test after test came back negative or inconclusive—and yet my physical condition continued to decline. After years of attempting to negotiate that I might never receive an answer and trying to come to terms with being a young woman at the start of her adult life who did not understand the changes happening to her body, I finally received a diagnosis: Ehlers-Danlos Syndrome. Classified as a rare disease, this

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<sup>1</sup> I make this distinction as this methodology relies heavily on the anecdotal. As such, I cannot testify to something which I have not experienced as I cannot do just to their lived experiences.

<sup>2</sup> This speaks to the tension in the interventions in the field and interventions in to the collective. While there are two distinct senses, these distinctions are sometimes blurred.

congenital condition is characterized by defects in the group of proteins which create collagen, the proteins that add strength and elasticity to connective tissue. This creates a myriad of comorbid conditions that are associated with the syndrome, primarily involving the skin, muscles, skeleton, and blood vessels dependent upon the subtype of the disorder.

Placed within a gray-space of being perceived as able-bodied, in a body sometimes requiring the use of mobility aids, I realized that this space needed to be explored. And, as a person living in this space of ambiguity, I believe phenomenology can create a rich account of living with rare difficult-to-diagnose and invisible illnesses that is currently beginning to emerge in disability studies. And, as Havi Carel theorizes, a phenomenology relies on the anecdotal; as such, this project will deploy personal narrative of what it is like to live with a hard to diagnose condition. This project begins with this insight, as it directs the progression of these ideas through personal accounts and towards questions such as inclusion within disability, processing diagnosis, and living in a world conducted by compulsory able-bodiedness and its normative values.

The lived experience of the body in illness and disability is commonly shrouded in stigma by the able-bodied hegemonic structure. Such an attitude is reflective of the healthy individual's distancing of itself from the spectrum of bodily abilities, and how these abilities may suddenly change or cease to exist altogether. This understanding is steeped in ideas of 'normality', which in this case refers to anybody that is free of disorder, physically and/or mentally sound, or healthy. Such can be found in the concept of the normate, "which can be understood as the ultimate ability exemplar, the exemplarity of which is shaped by and anchored in ableist assumptions that tells us how

bodies are and should be.” (Reynolds, 2019. 245) The problem here is both in the normative evaluation of bodies and the way in which conceptions of normativity shape what is legible. Illness and disability, in embodied reality, however, can be more properly understood as a spectrum. This spectrum of embodied experience also varies in intensity, highlighting the body’s precarious nature in terms of health. Bridging the gap between the intelligible experiences of the ill to the able-bodied must entail a descriptive first-person account. Phenomenology, “the study of structures of consciousness as experienced from the first-person point of view” (Smith, David Woodruff, 2013. “Phenomenology.” *Stanford Encyclopedia of Philosophy*) offers such a vehicle for delivering an intelligible experience of a complicated embodiment to the purportedly healthy and able-bodied person. While recognizing the contributions of classical phenomenologists, critical phenomenology provides a clearer avenue to bring these concepts to light. Critical phenomenology recognizes that we cannot make claims about lived experience in a generalized way: we must consider race, gender, sexuality, age, and disability status. In other words, we cannot bracket the identities which shape how we experience, interact, and engage with the world.

This project will consider how a phenomenological approach can be uniquely useful for feminist disability studies, particularly when thinking about “invisible” and hard-to-diagnose conditions, such as chronic pain and genetic disorders. In doing so, I will explore three central themes. First, I will demonstrate that bias in medicine has negatively pathologized the subject marked as Other: the ill, disabled, sexed, and/or racialized body, with reference to historical and contemporary evidence in disability studies and gender studies, as well as the history of eugenics in the U.S. Second, I will

provide a critique of the societal perceptions of disability and its influence on the lives of those with disabilities and chronic illnesses. Finally, I will formulate how phenomenology is uniquely beneficial in investigating concepts of embodiment and relationality regarding illness and disability. In doing so, I will build upon work in feminist theory, philosophy of disability, and especially phenomenological approaches to both fields to critically engage the violence of processes by which bodies are marked as intelligible. Within these fields, I will also consider distinctions in experiences of disability and illness, especially chronic illness, which is important because all too often bioethical discourses adopt a medicalized view of disability as a problem to be treated. Thus, all too often, philosophers – especially utilitarian ethicists – adopt the view that disability is “nothing more than a kind of biological disorder” (Barnes 1). The concept of disability as *not* inherently negative is one regularly treated with open skepticism.

Within theoretical and historical accounts, there is a long-established perception of the presumed quality of life for apparently disabled bodies. Feminist theorist Susan Wendell points to the shocking fact that nearly 90 percent of all philosophical articles on the topic of disability are quality of life determinations: under what conditions is it morally permissible to kill or leave disabled bodies to die and, concurrently, to what degree does a fetus need to be disabled before it is permissible to prevent its birth. As a result, Wendell argues that the theory of disability we need is a feminist theory of disability: not only because women make up half of the disabled population<sup>3</sup>, but because feminists have raised some of the most radical issues about cultural conceptions about the

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<sup>3</sup> As will be shown in Chapter 3, women are concurrently disproportionately affected by invisible disabilities.

body. Such an approach informs us of our preconceptions of normality and well-being, variables which have been attributed to the healthy body. The Western tradition, in turn, has defined disability exclusively as lack or privation. Such an underwriting conclusion draws upon Joel Reynolds's concept of the ableist conflation: [1] Disability is a lack or deprivation, [2] Deprivation of potential goods is a harm, [3] Harm causes or is a form of pain and suffering, [4] Given claims 1-3, disability is coextensive with (weak version) or causes (strong version), pain and suffering. Investigating the various claims made by canonical philosophers, such as Aristotle and Immanuel Kant, the ableist conflation is useful to determine the perceived pain, suffering, and disadvantage of non-normate bodies and their well-being.

The history of medicine has also perpetuated the idea of what the normate body should be: white, heterosexual, able-bodied male. In fact, the entire medical establishment has been based upon this established model of the body. This is not only a problem of individual bias, but a systemic issue. For example, the National Institute of Health implemented the *1993 NIH Revitalization Act*, establishing guidelines for including women and minorities as subjects in clinical trials.<sup>4</sup> The primary goal of such action was to provide scientific evidence leading to a change in standard of care or health policy, making the critical aim to determine if intervention or therapy being studied in women, men, or minority groups and their subpopulations differently. Before this legislation, there had been a shortage of data regarding drug efficacy and safety when

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<sup>4</sup> “The guidelines ensure that all NIH-funded clinical research will be carried out in a manner sufficient to elicit information about individuals of both sexes/genders and diverse racial and ethnic groups and, particularly in NIH-defined Phase III clinical trials, to examine differential effects on such groups.”

used by women and racial/ethnic minorities. An example of the dangerous effects of such policies can be seen in the use of the drug thalidomide. Used for its sedative effects, this medication was never approved by the FDA but had been used in neighboring Canada and throughout Europe. Because women, particularly of childbearing age, were not participants in Phase I or II of testing, data did not account for how the drug could potentially harm pregnant mothers. Thousands of women who took the drug while pregnant gave birth to babies with limb deformities, causing public outcry.

Implementation such as the 1993 NIH Revitalization act attempts to counter the subversive realities of exclusion in medical research, while recognizing the work that must be done to continue in the name of progress while also respecting that feminized and racialized bodies have been the site of medical experimentation.

Through establishing a framework that makes historical inequities in healthcare and research legible, I will analyze a history of oppression and exploitation of feminized and disabled bodies, and how pathophobic, misogynistic, and ableist assertions of power have harmed said minoritized bodies; of interest in this inquiry will be exploring bias in medicine. Using examples ranging from the early twentieth century to the contemporary moment, I will utilize Iris Marion Young's framework for oppression in tandem with Michel Foucault's analysis of docile bodies, especially as taken up by feminist theorist Sandra Bartky. The policy of coercions placed upon the body act to manipulate its gestures, its behaviors: the human body has entered a machinery of power that explores it, breaks it down, rearranges it. Discipline produces subjected and practiced bodies, requiring "an uninterrupted coercion be directed to the very process of bodily activity, not just their result; this "microphysics of power" fragments and partitions the body's time,

it's space, it's movements" (Bartky 277). Bartky elucidates the fact that we police our own bodies for the sake of the others, for the sake of fitting in to the greater social fabric of society. In other words, without conformity, one may be othered. I will further engage these concepts in chapter one of this project.

I will extend this critique next to the medical model of disability. The medical model of disability has been investigated by disability scholars as something that inherently highlights the bodies' impairment, rather than how the built environment disables them. The environment was constructed to support the healthy able-body majority based off of distinctions as to what a 'normal' body should be. The interpretations of normality have been used to pathologize bodies based upon interpretations of lacking, or abnormality. Yet, paradigms of health assessment of performance are culturally dependent. The medical model of disability relies upon distinguishing an ability/disability system, differentiating and marking bodies. Defining illness or disability as a result of an underlying physiological condition, intrinsic to the individual and which will reduce the individual's quality of life and resulting in clear disadvantages for the individual in question, the medical model fails to recognize the socio-cultural barriers created by society and the environment in accordance with compulsory able bodied ideals of energy, productivity, efficiency, and value. Determinations of need for basic social protections, such as life, liberty, and private property, while emphasizing a need for little government-led interference into these endeavors, assumes the disabled body's ability to participate in society, not unlike as an able-bodied individual. The medical model tends to follow the classical liberal conception of rights as negative in nature, and thus presumes an "independent," able-

bodied and rational subject, rather than seeing the value the disabled community places upon interdependency and establishing community. While doing so in theory, in political practice these theories advocate for the reduction of government interference in favor of market-based factors and ‘balancing social spending’. Such a suggestion perpetuates the economic hardship faced by much of the disabled community, who lack the necessary access to resources needed to make participation in society viable.

Through Chapter 1, I will explore the contributions of feminist theory and disability studies. These approaches illuminate one another, bringing in to question dominant concepts such as embodiment, corporeality, identity-based discrimination, and determinations of value. Recognizing that society is structured based upon ideals of the normate demands an interrogation of such structures, and how their effects maintain a disciplined population through the subversion of power to create docile bodies. In denying alternative knowledge and ways of knowing<sup>5</sup>, we deny the experiences of the disabled and chronically ill. Through the works of theorists such as Susan Wendell, Rosemarie Garland-Thomson, and Alison Kafer, I will explore the intersections between feminist and disability theory and how bias in medicine has affected diagnosis/prognosis, quality of life, and the greater question of being in terms of hegemonic and normate ideals.

Chapter 2 will focus on why phenomenology provides the most comprehensive and intelligible account of an alternative corporeal reality for those with chronic illness, disability, and hard-to-diagnose conditions. Understanding embodiment of the minority

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<sup>5</sup> Within the disabled community, this is otherwise known as crip knowledge.



body requires bracketing one's views and biases to understand the experience as is illuminates the first-person experience of living with disabling conditions. Critical Phenomenology recognizes that structural oppression cannot be bracketed and must be investigated in order to demand change. In order to make the experiences of the disabled community intelligible to the able-bodied majority, we must overcome the biases and stereotypes placed upon disabled bodies. This requires a detailed first-person account of living with disability in order to overcome the cultural ideas the disability is suboptimal, and consequently results in lower quality well-being. Phenomenology provides an avenue to make the disabled community's experiences heard, rather than silenced. Through the detailed analysis provided by Havi Carel, I will explore why phenomenology is the most useful method in making the experiences of the disabled individual intelligible to the able-bodied individual. It must be emphasized that this is a crucial aspect of creating a more equitable world for the disabled and chronically ill communities, as ideals of compulsory able-bodiedness permeate in to how we value the lives of others. Critical Phenomenology will question why the accounts of these individuals are not taken as credible, resulting in discrimination in society and medicine. The documentary series *Diagnosis* will provide case studies, which amplify the importance of individual testimony of the corporeal reality of the precarious embodiment of living with a difficult-to-diagnose condition. Testimony from these individuals does not come from the phenomenological perspective, but proves the connection between bias in medicine, the disjuncture between first-person and third-person experience, and the need for individual accounts of the lived experience of disability.

Chapter 3 will primarily focus on the reality of difficult-to-diagnose conditions. While there is a significant amount of work in disability studies on physical, cognitive, and psychological conditions, there is little in the field on the realm of difficult-to-diagnose conditions. Many of these conditions are invisible disabilities: conditions that aren't necessarily visible to society- however, these exist on a spectrum and could become visible during flares, the need of assistive devices, and so on. Informed by my personal experience, I will provide a phenomenological account of living with a difficult-to-diagnose condition within an able-bodied society that generally fails to recognize such conditions. Of particular importance to this is the experience of diagnosis. In attempting to navigate conditions that are difficult to diagnose, questions of agency, corporeality, and embodiment are faced with uncertainty. Utilizing Jen Scuro's work *Addressing Ableism: Philosophical Questions via Disability Studies*, I will explore the experience of diagnosis in addition to providing first-person experience of navigating the process of getting a diagnosis. Given my own lived-experience with Ehlers-Danlos Syndrome, a rare congenital disorder, I will provide a personal account of navigating such a process and navigating life in the grey-space of difficult-to-diagnose conditions.

These ideas transform the intelligibility of the experience of difficult-to-diagnose and invisible disability. Through the investigation of the above concepts, alternative conceptions of well-being and quality of life can transform the biases and stereotypes placed upon the minority body within a society that establishes able-bodiedness as normate. Phenomenology provides an avenue to combat the bias faced in the medical establishment, fostering a clearer sense of understanding in the doctor-patient relationship. Improvements in quality of care and understanding validate the experiences

of the disabled community, empowering them to advocate for their own health and resources. In instances of difficult-to-diagnose conditions, phenomenology elucidates the difficulty in diagnosis, prognosis, and the management of symptoms in an environment that challenges the body. Overall, phenomenology provides the answer to challenging the structural problems faced by othered persons, and questions how we can change them.

**Chapter I:**  
**Feminist Theory, Disability Studies, and Queer Theory: Relations of Body and  
Identity**

Feminist theory has and continues to inform topics related to the body and identity politics, with concern for how social factors shape the body's formation.

Intersectionality, coined by Kimberlé Crenshaw and popularized by black feminists as the insight into the interconnected nature of social categorizations such as gender, race, class, disability, and so on, has primed feminists to explore how the interconnectedness of these factors lead to discrimination and/or disadvantage. As such, feminist theory is mutually informed by disability studies and queer theory through shared, overlapping concerns with mind/body dualisms, compulsory norms, and issues of inclusion and oppression.

To understand the relationships between able-bodiedness and disability, one must understand the concepts which shape the relationship between the mind and body.

Foundations of these concepts can be traced back throughout the history of philosophy, with Descartes' formulation of these ideals in the mid 17<sup>th</sup> century among the clear influences on this distinction. Feminist philosophers such as Susan Bordo, Genevieve Lloyd and Elizabeth Grosz offer analyses of these historical dualisms through a feminist lens, with concern for the way they tend to relegate those who are "othered" vis-à-vis dominant norms to the devalued side of the binary. If Western culture values mind, reason, and culture, it correspondingly devalues the terms opposed to these. Further, this

association with devalued terms such as body and emotion serve to normalize their marginalization and oppression, consequently shaping compulsory norms of able-bodiedness, misogyny, white supremacy, heteronormativity, and so on; compulsory norms reinforce hegemonic ideals of normativity, to the detriment of who are not white, heterosexual, able-bodied and/or cisgender males.

This section will lay out some of the basic concepts that inform the logics of ableism and how these deeply engrained values marginalize and oppress othered peoples. Using these concepts, I will draw the connection between feminist theory, disability studies, and crip theory to accessibility to medical care and the dominant masculine and able-bodied norms that govern society and our conception of practicing medicine through the case of Ashley X. I will explore the significance of diagnosis/prognosis, quality of life, and the greater question of being in relation to the dilemma of her treatment as a female and disabled individual. The intersectional dimension of this case demonstrates how identities can compound to stigmatize and control such persons based on hegemonic norms. As such, it deeply illustrates the mind/body distinction imposed upon the disabled body. I believe this is important to make clear, as these concepts point towards a need for a language and theory of knowledge that makes the experiences of these individuals intelligible to those within the able-bodied majority, underscoring the need for a phenomenology of illness.

## **Dualisms**

Feminists have had a complicated relationship to the body as a concept due to the historical devaluation of women, all too often associated with the lesser half of the

mind/body dualism: the body. Binaristic thinking prioritizes and ranks the two polarized terms, resulting in one becoming the privileged term while the other becomes its negative and subordinated counterpart. Cartesian dualism reinforces this mind/body distinction and the prioritization of the mind (maleness) over body (femaleness), reinforcing classical dualisms ideals which can be traced as far back as Plato's *Phaedo*. To understand this, one must know that "What Descartes accomplished was not really a separation of mind from body...but the separation of soul from nature." (Grosz 6). Distinguishing between a thinking substance (*res cogitans*, or mind) from extended substance (*res extensa*, or body), only the latter could be considered a part of nature and governed by its physical laws.<sup>6</sup> This theorization separates the subject or consciousness, and could reflect on the world of the body, nature, objects, and so forth.

The relegation of women to the sphere of the passive, natural body, did not originate with Descartes but can be traced back to Plato and Aristotle. While Plato argued that the body is a treacherous prison for the soul/reason/mind, Aristotle took this argument further by continuing Plato's maternity argument: the mother as a receptacle or nurse of being (rather than the role of a co-producer)- to state that the mother provided the passive and formless matter that the father would give shape, form, and contour to. The distinction drawn between mind/matter by Plato and Aristotle transforms into the mind/body distinction drawn by Descartes, transferring the status of woman as the passive/formless to the natural, prescribing body to remain in lesser status to the mind. As

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<sup>6</sup> *Res cogitans*, the thinking substance, has no place in the natural world. In excluding the mind from the natural world, Descartes succeeds in making the mind the foundation of knowledge, or "a science of the governing principles of nature" (Grosz 6)

such, women have been relegated to this subordinate status since ancient times all justified by these theories.

Feminist theory has attempted to reconceptualize this status and distinction. While Cartesian theory believes the body to only be an “organic and instrumental functioning in the natural sciences or [is] posited as merely extended, merely physical, an object like any other” (Grosz 8), feminists have questioned how philosophers had linked reproduction to vulnerability, consigning women to be always in need of protection. This reasoning is justified by the patriarchy’s evaluation of the female body’s corporeality<sup>7</sup>. With the male/female distinction being closely allied with the mind/body distinction, this has consequently been aligned with different conceptions of corporeality based upon gender differences. This logic presumes females to be naturally unequal, and a patriarchal order relegates women to a different standard in terms of physical and cognitive abilities and in social situations.

As such, the body cannot be understood neutrally, as “a biological tabula rasa onto which masculine and feminine could be indifferently projected” (Grosz 18). Developing alternative knowledges of the body disrupts the status and structure of existing knowledges, and the relations of power that govern sexual, racial, able-bodied norms which prioritize a dominate universal model of subjectivity. Articulating the differences and similarities between the subjectivities of the mind/body dichotomy requires understanding the body as cultural object: the product of social, political, cultural, and geographic inscriptions. The narrow constraints of culture limit our conceptions of how to think about materiality and can be thought through altogether new

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<sup>7</sup> “Bodily: our corporeal nature is our bodily nature” (Blackburn 108).

conceptions of corporeality. While this extends the scope of my project, I find rich resources here in feminist and queer theory as well as disability studies for their challenges to the compulsory acceptance of dominant norms and knowledges.

Disability studies has also made significant contributions to how the body and the relegation of normal/abnormal has marginalized those with impairments. Stigmatization of one's quality of life and purpose to one's physical or cognitive ability denies these individuals assertion to their own subjectivities. Through the pathologization of the disabled body to the abnormal in social, medical, and other institutional settings, disabled individuals become a spectacle rather than subjects worthy of respect. Rosemarie Garland-Thomson states that this division of normal/abnormal equates to the usual/unusual, so that these individuals become hyper visible; 'demanding' the attention of others. Hegemonic thought processes highlight individuals that do not fit into the dominant framework; modernity and its logic has made society more homogeneous, putting those interpreted as 'different' in the spotlight. We use visual cues to determine our course of action through our interactions with others, directly correlating to the fact that how one looks or acts directly correlates to how we perceive them (or do not) as subjects. By sorting through perceptual indicators, we categorize unknowns around us to respond to them. This response is informed by what Joel Michael Reynolds calls the ableist conflation: the belief that disability is a lack or deprivation, this deprivation of potential goods is a harm which is a form of pain and suffering, and given these claims disability is therefore coextensive with or causes pain and suffering. This claim brings critical attention to the assumptions one might make in their corporeal expectations of others, both those deemed 'normal' and those who are held to different. Compounded



with the reality of having a different embodiment and corporeality, predominant beliefs of the presumed undesirability of disability have resulted in these individuals' lives and experiences to be devalued.

### **Compulsory Norms**

Dualisms, which necessarily hierarchize subjectivities, inform our knowledge of *how* to subjugate the body. The need for docility, the ability to manipulate bodies in a coercive manner, has been demonstrated and performed upon populations by those in power *en masse* since the eighteenth and nineteenth centuries—a resulting effect of the Western Enlightenment and scientific revolution. The ability to sculpt the body into an object of dominant culture necessarily implies an underlying vector of power, practiced upon the body to make it 'fit in'. This is to say that this knowledge of the body—one which is not the biological science of its functioning—and the mastery of its forces would be constituted as a political technology of the body, according to Michel Foucault (1975). What apparatuses and institutions wield is, as Foucault (1975) writes, “a microphysics of power, whose field of validity is situated in a sense between these great functionings and the bodies themselves with their materiality and forces” (26). Such power is a strategy of domination, exercised rather than possessed, such that our bodies are not so much dominated or repressed as rendered “docile” so that power speaks through us. Foucault claims we should admit that power produces knowledge, and that the two directly imply one another. This insight is important for disability studies as well as for feminist and queer theory.

These concepts are furthered in Foucault's later work on biopower (1976), in analyzing the distinction between the heterosexual and homosexual, as can be seen by the studies of sex that began to gain in popularity during the nineteenth century. The objective here is to analyze a certain knowledge regarding sexuality as an especially dense point for relations of power. While sexuality is not the most easily controlled or directed element in power relations, it is one of greatest instrumentality. Through the hystericization of women's bodies, a socialization of procreative behavior, and the psychiatrization of perverse pleasure, power attempts to gain control of sexuality. These processes are the very production of sexuality; sexuality cannot be considered a natural given, obscured from knowledge, but rather as a historical construct. Through the deployment of alliance, and the social expectation to create heterosexual nuclear families, homosexuality became subordinate to the norm of sexuality; heterosexuality became the dominant norm, relegating homosexuality to be subordinate – despite the fact that homosexuality as a practice existed before such categorizations.

Adrienne Rich builds upon this notion with the concept of compulsory heterosexuality: “a system of oppression that denies people's sexual self-determination by presenting heterosexuality as the sole model of acceptable sexual and romantic relationship.” (“Compulsory Heterosexuality and Lesbian Existence”, *Signs* 5(4), pp. 631-660 (Summer 1980). Rich's analysis highlighted heterosexuality's dominance within patriarchal society because it passed as a universal status, made compulsory through patriarchal order and naturalization. As Robert McRuer (2020) has written, crip theory has taken this articulation of compulsory norms and applied it to the naturalization of able-bodiedness, which is “simultaneously assumed to be the supposed natural state of

any body and yet is a state that all of us are striving to attain or maintain” (62). Like heterosexuality, able-bodiedness passes as the perceived “natural” (read *dominant*) state of things due to its uninterrogated attachment to ideas of what “normal” is. This is based in the belief that “healthy” is “normal”. Bodies that are unable to function productively within culture’s expectations of how a body should function are subordinate to those that can; the disabled body becomes “othered” through these experiences of what Rosemarie Garland-Thomson (2020) calls “misfitting”.

### **Inclusion and Oppression**

The effects of dualism and compulsory norms are subsequently in line with patriarchal knowledge. Those who are not white, cisgender, male, heterosexual, able-bodied persons are subject to varying degrees of exclusion from dominant culture. However, this exclusion comes in many forms, embedded within quotidian existence such that othered groups are subjected in various ways to the universal subjectivity of white, cisgender, heterosexual, young and able-bodied bourgeois men. Many deny that sexism, racism, ableism, agism, and homophobia are alive and well within Western contemporary societies because these ‘isms’ were legitimated through scientific theories of group inferiority associated with the past. This logic makes sense within the well-intentioned liberal society: in societies that are publicly dedicated to formal equality, matters such as gender, age, race, sexual orientation, and bodily ability should not be factors in dealing with individuals because we should be relating to others as individuals only. This ideal promoted by this arrangement should mean that group differences do not matter in our everyday encounters with one another; these factors are supposed to make

no meaningful difference in how we treat one another. what Iris Marion Young (1998) describes the gradual change of dealing with difference as one from discursive consciousness to that of practical consciousness,<sup>8</sup> which means that discrimination has generally, but not entirely, moved from the realm of the public to the private, from that of overt oppression to a subverted, cunning oppression that lies within the structures of a society's subconscious. In a society which claims a commitment to formal equality, such unconscious reactions are far more widespread than the discursive prejudice and evaluation previously embraced, and do not rely on the latter to reproduce relations of oppression and privilege.

As such, we must recognize the ways in which oppression is enacted upon othered groups to understand its contemporary formularization. Traditionally, oppression has meant the exercise of tyranny by the ruling, or universalized 'neutral', group over others. However, as Young (1998) observes following the social justice movements of the 1960s-70s, the meaning of oppression has shifted to designate "the disadvantage and injustice [that] some people suffer not because of a tyrannical power coerces them, but because of the everyday practices of a well-intentioned liberal society" (41). Oppression in this sense is affirmed as *structural* rather than the consequences of a few people's decisions or policies. In order to understand oppression as structural and systemic in this way, one must recognize what group identity is and its implications. To do so, in this section I draw upon Young's (1998) theory of the five faces of oppression, which allows

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<sup>8</sup> Whereas, for Young (1998), discursive consciousness names "those aspects of action and situation which are either verbalized, found on explicit verbal formula, or easily verbalizable", practical consciousness on the other hand names "the habitual, routinized background awareness that enables persons to accomplish focused, immediately purposive action" (131).

me to identify how oppression shapes the lived experiences of those who are variously “othered”. Through the concepts Young offers, one can grasp the precarity of living as the marginalized other. Using specific examples raised by feminists and disability theorists of how these systems operate will help to illuminate why an equitable society for othered individuals is both pressing and necessary.

Understanding how oppression operates requires defining a social group. Young identifies a social group as a collective of persons which are differentiated from one or more other group(s) by cultural forms, practices, or way of life. It is the conceptualization of group difference in terms of an alienable nature that is essentially different from that of the ‘universal’ group that creates the dynamic of group hierarchization, determining what groups and their members deserve, are capable of, or their exclusion entirely. Thus, Young formulates a theory of oppression that takes in to account the intersectional nature of identity, and how these factors compound to impose multifaceted experiences of oppression. She categorizes five key contemporary forms of oppression: exploitation, marginalization, powerlessness, cultural imperialism, and violence, with the aim of offering criteria for determining whether and to what extent various groups are oppressed.

Exploitation generally refers simply to the use and/or development of resources. Within moral and political philosophy, following the Marxist critique of exploitation, this “applies specifically to an unjust economic and social relationships whereby one class can take advantage of the labor of others” (Blackburn 169). The labor theory of value explains how every commodity’s value is in direct relationship with the labor time necessary for its production. While critique of capitalist practices is a generative source

of ideas regarding distributive justice and equality, I cannot cover this within the scope of this project. I am, however, interested in the implications of this economic theory and to indicate that the concept of exploitation is a concept of oppression.

The injustice within capitalist societies is the private ownership of the means of production, allowing some to gain the benefit of others' labor for their own purposes. The oppressive nature of exploitation occurs, then, through the steady process of transferring the results of the labor of one social group to benefit the other (49). A structural relation is therefore in place between social groups, determining what work is, who does this work, how one is compensated, and so on. Along these lines, feminists have easily demonstrated that women's oppression consists partly in a systemic and unreciprocated transfer of powers from women to men (50). This transfer is twofold: the transfer of material labor and the transfer of nurturing energies and sexual intimacy. As such, this directly relates back to the belief that women are passive in form: they are well-suited for smoothing over interactive tensions (read personal), rather than interacting in the charged, active public sphere with its interactive dynamics- better suited for men. Such expectations exist not only within the structure of the nuclear, patriarchal family, but extend to the workplace and the state.

Marginalization, the treatment of a social group as insignificant or lesser-than, excludes a whole category of people from meaningful participation in social life, thus subjecting them to material deprivation and potentially death. The individuals affected are marginals: those whom the system of labor cannot or will not use (53). In the United States, there is a vast pool of individuals deemed marginals: the elderly, people of color who cannot find a job to start building work experience, single mothers, the involuntarily

unemployed, indigenous Americans, the disabled. For this reason, Young identifies marginalization as one of the most dangerous forms of oppression, because an entire category of people are expelled from useful and meaningful participation in social life. Marginalization extends from the individuals excluded for citizenship by early bourgeoisie liberalism, because they were viewed as dependents, such as women, children, those with physical or cognitive disabilities or the institutionalized. Dependency thus implies a permissible right to suspend one's basic rights to individual choice, respect, and privacy. It is critical to note that dependency in itself is not oppressive: the individualistic assumption of moral agency and autonomy is instead at issue. Feminists have argued for a model of justice that recognizes the inherent value of all, including dependents; "Dependency should not be a reason to be deprived of choice and respect, and much of the oppression many marginals experience would be lessened if a less individualistic model of rights prevailed" (55). As an example of marginalization and resistance to this form of oppression, the disabled community recognizes the need for dependency based upon the lived realities of having a body whose ability differs from the average individual. No matter the capacity- cognitive or physical- people within the community recognize the need for mutual aid in order to not only live a day-to-day existence within a system that institutionalizes those deemed critically ill or disabled by bureaucratic administrators, but in order to advocate for the needs of the community as a whole.

Powerlessness, the underlying phenomenon of exploitation due to capitalist class structure, highlights the fact that some people have wealth and power because they have profited over the labor of others. Professionals are privileged in regard to

nonprofessionals in the workforce, as nonprofessionals lack the status and autonomy within the labor force to make decisions. This form of oppression adds to the injustices of exploitation by further exploiting those whose labor produces profit primarily for capitalists rather than workers. The powerless, by definition, lack a mediated authority or power within the workplace, situating these individuals within the position of needing to take orders from others while rarely having the ability to give orders to others. Division between professionals and nonprofessionals creates an accompanying reality that minimizes opportunity for the development and exercising of skills. Such privilege extends past the workplace, where nonprofessionals lack work autonomy and technical experience, and into the realm of respectability<sup>9</sup>. The centrality to the point of powerlessness as exploitation revolves around the notion that the basic division of labor deemed essential by capitalist societies: division between the professionals who plan and the nonprofessionals that execute.

These three factors, exploitation, marginalization, and powerlessness occur by virtue of the social division of labor present within modern capitalist nations. Such factors affect the material realities of life, and yet oppression is not limited to this type of deprivation. Feminists and black liberationists have pointed to another kind of oppression: that which dominates societal expectations, standards, and norms. Cultural imperialism is one of these pernicious social phenomena that determines the experience of “how the dominant meanings of society render the particular perspective of one’s own group invisible at the same time as they stereotype one’s group and mark it out as the

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<sup>9</sup> By respectability, Young means the respect presupposed to an individual based upon the merit of their expertise or knowledge, which gives way to autonomy (if limited) within the workplace, plus generally demand that said individual be listened to.



Other” (56-57). Subsequently, this creates a paradoxical relationship in which the culturally imperialized are othered (and therefore invisible) while being stereotyped as having an ‘essence’ that marks these bodies as worthy of being deemed less rational, less believable, or sometimes more perverse. In short, these peoples are silenced as knowers. Stereotypes become internalized and processed through what W.E.B. Du Bois called “double consciousness,” as they project a caricatured formulation of the culturally imperialized group(s) lived realities, enforcing a reactive dimension to how others interpret themselves (60). The manufactured space of otherness creates specific experiences unavailable to the dominant culture due to the fact that said experiences vary greatly upon the factor that oppressed groups are often socially segmented. Double consciousness thus names the phenomenon of being defined simultaneously by the dominant culture and a subordinate culture. This experience of being marked out as different while also being made invisible comes as a direct result of the dominant group failing to recognize that their perspective of culture is just that—a perspective.

I find a powerful example of cultural imperialism toward disabled people, as well as resistance to this imperialism, in the spring of 2020, when San Francisco disabled activists organized to distribute necessary supplies to the most critically endangered of the community during the covid-19 outbreak that shut the country down.<sup>10</sup> While immunosuppression during a pandemic can make disability or chronically illness a much more daunting reality, this community took collective organization to ensure those who needed care could still receive it. However, much of this work was done under the shroud

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<sup>10</sup> “Disabled Advocates Fear Discrimination, Supply Rationing amid Coronavirus Pandemic.” *Fox 2 KTVU*, 9 Apr. 2020, [www.ktvu.com/news/disabled-advocates-fear-discrimination-supply-rationing-amid-coronavirus-pandemic](http://www.ktvu.com/news/disabled-advocates-fear-discrimination-supply-rationing-amid-coronavirus-pandemic).

of the fear of ableism: with ventilators in such short supply, disability rights advocates and disabled people grew increasingly concerned that they would not be prioritized for medical equipment due to the negative perception of disabled people's quality of life and life expectancy itself. Rather than engaging with the disabled community to determine how they view their everyday experiences, the dominant culture prescribes a diminished sense of well-being and quality of life to disabled bodies which justifies the means of withholding valuable resources with preference to the able-bodied and presumably "healthy"—her body was too weak to fight of the virus anyway, why should we waste valuable resources on her when we could potentially save someone else?

The final face of oppression identified by Young is violence when it is systemic in nature. Faced with the actual threat of violence by the dominant culture who threatens one's existence as an othered person, one responds by self-policing to act in a manner which is perceived as acceptable. Sandra Bartky (1988) argues that these coercions placed upon the body act to influence its gestures, its behaviors: the human body has entered a machinery of power that explores it, breaks it down, rearranges it. In other words, the fact that we discipline our own bodies for the sake of the others in order to conform to the dominant culture's values. Action or any form of outward expression that may be defined as deviating from the accepted values or practices by the dominant culture brings the possibility of the threat to one's safety. Knowledge of this nature involves a basic understanding that one may face, and therefore fear, random unprovoked attacks upon their persons or property with no motive other than to humiliate, damage, or destroy the person in question. What makes violence oppressive is that while these instances are admittedly horrible, the social circumstances surrounding these acts make

them de facto permissible, since they are so rarely punished in practice. In other words, violence committed against those who are othered is socially acceptable because they do not fit the paradigm of normality; their existence alone justifies the violence committed against them.

We see this demonstrated through hate crimes such as the Sagami-hara stabbings that occurred in 2016 at a care facility in Japan. Nineteen disabled people ultimately died, and dozens of others were injured, during the spree. Satoshi Uematsu stated in court that he committed the crimes because he believed it would benefit society; Uematsu has even been quoted stating to investigators that he believed those with disabilities “had better disappear”. Such an abhorrent, violent act illustrates a societal devaluation of disabled lives persists to this day. Another example would be the sheer fact that one third to a half of all people killed by police in the United States are disabled.<sup>11</sup> When disability is left out of these conversations and coverage, we miss how disability intersects with various other factors that result in police violence.

This violence-causing hatred or fear experienced towards the othered, to some extent, involves insecurities on behalf of those inflicting violence upon the othered. Unconscious processes are playing out, and Young theorizes much of this fear that leads to oppression and violence is wrapped up in fears of identity loss (63). The manner in

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<sup>11</sup> In their 2017 report, “Media Coverage of Law Enforcement Use of Force and Disability” the Ruderman Family Foundation found that “Disabled individuals make up the majority of those killed in use-of-force cases that attract widespread attention. . . . The media is ignoring the disability component of these stories, or, worse, is telling them in ways that intensify stigma and ableism.”

which cultural imperialism intersects with violence creates a dissonance between the dominant culture's claim to universality and the subjectivities of the oppressed.

Propagation of ableist ideas and values depends on this insecurity: facing individuals with the reality that their body may not be what it seems, that disablement can happen to them.

### **The Case for Young**

In this chapter, I have spent a lot of time engaging with the ideas of Young. I do so as Young shapes the approach to thrownness in a critical manner that begins to shape a groundwork for a critical phenomenology. With the field emerging in a more concrete sense over the past decade, Young was groundbreaking in the sense that she was performing some of the same critical interventions back in the 1980s. For example, Young makes the point in her essay "Throwing Like a Girl" (1980) that gender shapes one's thrownness and is an integral structure of experience which must be engaged with as such. Following this line of reasoning, one cannot simply speak from a universal standpoint on experience: factors such as disability, race, sexuality, and so on, must therefore be interrogated through the same critical approach; as these social markers are indivisible from one's thrownness, we must take them into consideration. In theorizing how social factors deeply and profoundly shape our experiences, she is indirectly gesturing towards the quasi-transcendental nature of the distinctions placed upon categories of persons and the phenomenon of racism, sexism, ableism, homophobia, transphobia.

Through providing a comprehensive intersectional approach to the process of oppression, Young provides a launching point to establish critical interventions in the

world. Factors such as gender deeply effect our ability to negotiate spaces, down to the manners in which one can physically move their body:

“We often experience our bodies as a fragile encumbrance rather than the medium for the enactment of our aims. We feel as though we must have our attention directed upon our bodies to make sure they are doing what we wish them to do, rather than paying attention to what we want to through our bodies.” (34, 1980)

In lacking the trust in our bodies to carry us to our aims, as our means of having a world, Young argues that gendered experience is an inhibited intentionality: reaching towards a projected end, an “I can”, while simultaneously withholding full bodily commitment to said end with a self-imposed “I can’t”. One can naturally extend this line of reasoning and lack of bodily action to the restrictions placed upon othered bodies, such as disabled bodies, by normative societal values and the physical and social environment that has been consequently been constructed. In establishing these critical insights and interventions, Young asserts the connectedness between being and one’s social identity as indivisible and therefore as a foundational aspect of understanding one’s being-in-the-world.<sup>12</sup>

### **Working Towards a Phenomenology of Illness**

As I have demonstrated, the intersections of identity and otherness are deeply integral in understanding relations of body and identity. Tracing back the relationship between the mind/body dualism which justifies the othering of bodies that do not fit the mold of white, cisgender, heterosexual, able-bodied male shows how theorists and those in positions of power have utilized this line of thinking. To this day, this thinking

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<sup>12</sup> For phenomenologists, such as Heidegger, the notion of Being-in-the-world provides us with a reinterpretation of the act of existing.

underlies the oppression othered bodies experience on a day-to-day basis in the form of marginalization, exploitation, violence, cultural imperialism, and powerlessness.

Feminists, disability theorists, and queer theorists have deployed such critiques to deconstruct the hegemonic order which marginalizes othered bodies, and also to conceptualize the lived experiences of disabled, gendered bodies.

In the next section, I will explicate why phenomenology is the optimal method for understanding the realities of living with disability and chronic illness. In doing so, I will develop a phenomenology of illness which establishes the lived experience of not only living with disability but living with invisible disability and chronic illness. By investigating the grey space in the spectrum of the lived realities of living with impairments, I hope to develop a clearer understanding of the importance of taking individual testimonial seriously in the accounting of one's lived experience as an othered person existing within a world that devalues those who cannot 'live up' to the biological ideals of health and normality.

## **Chapter II:**

### **Phenomenology: Elucidating Lived Experience**

Given the impacts of oppression against othered subjects, the lived experiences of these individuals vary greatly from those who occupy positions of relative privilege. Consequently, to understand the lives of those who are oppressed, we must use alternative knowledges to illuminate the quotidian existence of the oppressed. Through incorporating new methodologies to better understand the lived experiences of others, we can begin to comprehend alternative embodiments and corporealities in a manner that respect other's bodily autonomy and worth. In this section, I will be drawing on phenomenology as a methodology to do just that.

Phenomenology examines the encounter between consciousness and the world in a manner that is human-dependent. In other words, phenomenology is the science of relating consciousness to appearances instead of things as they are. The lived body as we experience it happens through the first-person perspective. As such, perception is an embodied activity- this claim is not just an empirical claim but a transcendental view which positions the body as the condition of possibility for perception and action. For thinkers such as Maurice Merleau-Ponty (1908-1961), perceptual experience is the bedrock of subjectivity. Due to the inseparable nature of embodiment, perception, action, and subjectivity, changes to one's body frequently lead to changes in one's sense of self and being-in-the-world. This leads to disjuncture between forms of embodiment and

ways of being as the body is a subject-object, holding a unique space that belongs to both first-person and third-person point of view. In other words, while the body is foundational to perception and subjectivity, it is also physically matter. This fact ultimately affects how the body is inserted in the world, and how it interacts with it.

For this project, I draw from the distinction between critical phenomenology and classical phenomenology, though I take lessons from both lines of inquiry.

Phenomenology offers an avenue for articulating embodiment in a manner that highlights its situated, precarious nature, making it the optimal methodology for explicating chronic illness, hard-to-diagnose conditions, and disability. Critical phenomenology will question why these accounts are not taken as credible, resulting in discrimination in society and medicine.

While there are many philosophers of disability that use this method, Havi Carel offers a unique perspective on making the chronically ill bodily experience intelligible to the able-bodied majority. Experiencing Lymphangioleiomyomatosis (LAM), a rare disease which causes muscle-like cells to grow uncontrollably in organs and tissues such as the lungs, kidneys, and lymph nodes, Carel offers a unique insight into the experience of illness, arguing that illness is fundamentally a phenomenological disruption that allows us to analyze a change in embodiment, bodily alienation, and bodily doubt which characterize it.

To demonstrate this in application, I will utilize the docuseries *Diagnosis* to give examples of how the medical system becomes difficult to navigate and explore the complications in receiving a diagnosis when experiencing a rare condition. The testimony provided by these individuals is not phenomenological in nature *per se*, but demonstrates



connections between bias in medicine, the disjuncture between first-person and third-person experience, and the need for individual accounts of the lived experience of disability.

### **Phenomenology and Critical Phenomenology: Drawing the Distinction and Laying the Foundation for a Phenomenology of Illness**

Phenomenology, the meaningful study of the structures of experience and consciousness, begins through the bracketing of the natural attitude, or the assumption that the world exists apart from one's consciousness, and the reduction of quotidian experience of being-in-the-world to basic structures which subsequently establish coherence. Such reduction does not operate to isolate from the complexities of quotidian existence, but rather direct back from the uncritical attendance in the world to a more vigorous understanding of the circumstances for the possibility of the world whatsoever. The most fundamental of these conditions is the transcendental ego; as Lisa Guenther (2020) writes, "there is no experience, and hence no meaningful experience, without someone who does the experiencing" (11). Experience is inherently dependent upon perception; it is constantly ongoing, forming perception(s) in tandem with the lived experience as they occur. Such a process is dynamic in nature. Therefore, the individual who experiences is not, as Descartes described, a bare *cogito*, but has feelings and memories. Guenther writes:

If I am not just a bare cogito, but a relation or orientation of an intentional act (thinking) to an intentional act (thought), then even at the level of absolute individuality, I do not exist as an isolated point, but rather as a vector or arrow that gestures beyond itself in everything it thinks and does (ibid).

This gesturing-towards begins to explain the movement of phenomenology towards something, but what then is the object of this gesture, if the subject no longer exists as an isolated point? While classical phenomenology points us in a critical direction, critical phenomenology can more sensitively describe experiences in which one cannot bracket in the same way due to the sociohistorical context in which one experiences being-in-the-world. In other words, it fails to give an account of social structures and historical contingency which shape our experience in a quasi-transcendental manner (ibid, 12); it fails to take one's thrownness into the world into account as a factor that fundamentally shapes perception. As such, turning to Merleau-Ponty will both demonstrate the turn towards critical phenomenology Guenther describes and a basis for establishing a phenomenology of illness.

For Merleau-Ponty, the body takes on a dual role: it is a physical thing which can be observed and measured from a third-person perspective, but it is also the source of subjectivity- the place where consciousness occurs. To reiterate, this makes the body a subject-object, a being that can be experienced in both first and third person perspectives. For the purposes of a phenomenology of illness, Merleau-Ponty's conception of the notion of motor intentionality is necessary to synthesize the concept of the subject-body with previous phenomenological conceptions of mental phenomena having intentionality<sup>13</sup>. Merleau-Ponty argues that this intentionality can extend to the body: directing itself towards objects, goals, and 'acting' in various ways towards objects and aims. In staking this claim, Merleau-Ponty asserts that bodily intentionality is in fact the

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<sup>13</sup> "the power of minds and mental states to be about, to represent, or to stand for, things, properties and states of affairs." (Jacob Pierre 2019. *Intentionality*. Stanford Encyclopedia of Philosophy)

primary, and foundational aspect, of mental intentionality. Through doing so, motility is seen as basic intentionality, which ultimately reiterates Edmund Husserl's (1859-1938) claim that consciousness is not a "I think that", but a "I can" (Merleau-Ponty 2012, 139 and see Husserl 1988, 97, cited in Carel 33). Such mental intentionality cannot exist without bodily orientation in the world; thus, as Carel (2016) writes, "Consciousness is being towards the thing through the intermediary of the body...to move one's body is to aim at things through it" (33). As such, motor intentionality is embedded in the concept of the intentional arc, a term coined by Merleau-Ponty which describes our relationship to the world. This relationship "includes a layer of motor intentionality but also a temporal structure, a human setting, and a moral and existential situation" (ibid). In this sense, the concept captures how the human experience in the world is not merely physical, but shaped by cultural and social meanings, making this ultimately an existential situation. The intentional arc, therefore, unifies the sensibility, cognition, motility, and the physical. As Merleau-Ponty formulates, it is this intentional arc that is distributed in illness.

While Merleau-Ponty established a basis towards a more critical approach to phenomenology, modern day phenomenologists have pushed these concepts further to tackle one of classical phenomenology's larger flaws. Lisa Guenther (2020) draws a critical distinction between classical phenomenology and critical phenomenology that illuminates the differences between these two applied methods:

A crucial difference between classical and critical phenomenology is the degree to which intentionality is understood as the orientation of an intentional act (noesis) toward unintentional object (noema), where noesis constitutes noema without being reciprocally constituted by it, or as a relation in which feedback loops interweave noetic processes with a noematic field and vice versa (12).

While classical phenomenologists such as Husserl take the former position, Merleau-Ponty employs that latter through his employment of the chiasmatic structure of intercorporeal being-in-the-world. This position provides a launching point for critical phenomenology simply because it recognizes the substance of the world without treating it as an adamant determinative force.

Critical phenomenology goes beyond classical phenomenology in the sense that it reflects on the quasi-transcendental social structures informed by organizations of power which makes experience of the world comprehensible while concurrently engaging in the practice of reconstructing the world for more liberating possibilities for a more meaningful existence. Such structures of power, such as ableism, patriarchy, white supremacy, and heteronormativity reproduce in the natural object by which we make our observations and experiences. While there is nothing necessary about these structures, they have informed and continue to inform our perceptions of objects and subjects in a meaningful way. We overlook such factors using the classical phenomenological method to our own detriment because such factors are necessary to bracket to study a questionably 'objective' form of the experience of consciousness. Ultimately, critical phenomenology's goal is not only to interpret the world in which we are thrown into, but to also change it. Through understanding the hegemonic order by which oppressed persons experience being-in-the-world, we can reimagine a more equitable world for all. In the following section, I consider along these lines how critical phenomenology can be a powerful methodology for disabled being-in-the-world, especially when a disability is not readily visible to others.

## **Phenomenology of Illness: Establishing a Foundation for Understanding Illness**

Having established these basic concepts and framework, we can now begin working towards an understanding of how this methodology speaks to feminist phenomenologies of illness. To do so, we must set up some basic understandings of under what circumstances this phenomenology will operate within. Firstly, a phenomenology of illness commits itself to focusing on the more profound experiential changes associated with serious illness, where the onset of illness is not followed by complete recovery within a short period of time. Secondly, as Havi Carel claims, the personal and anecdotal are essential to this type of philosophical inquiry and are in fact what motivates it. Because our fundamental sense of embodied normalcy becomes disrupted when an individual falls chronically ill or disabled, calling for the examination of one's individual life, goals, meaning, and values – and how to modify them in response to said illness – becomes crucial.

But what is illness within this context? Carel defines “illness” as “the experience of disease, the ‘what it is like’ qualitative dimension as it is experienced and made meaningful by the ill person” (17). This includes experiencing one's bodily changes and symptomology, as well as navigating the public sphere of social interactions and healthcare. In doing so, one encounters the barriers of widely held ableist beliefs of poor quality of life for those experiencing illness and disability, grappling with pain, facing questions of mortality, and navigating a hostile world.

It is of utmost importance to note, for the sake of this project, that illness encompasses a wide variety of experiences. Due to the scope of these experiences, I cannot possibly provide a nuanced account of the full spectrum of disabled and

chronically ill experience. While many people classified as physically and/or cognitively disabled or chronically ill face oppression and discrimination due to their non-normate embodiment, these experiences are deeply informed by the disease(s)/dysfunction(s) which underlies each persons' life. As such, one must distinguish between an illness which results in a temporary loss of ability, in which one is confident that said ability will be regained, and illness in which loss is uncertain, progressive, enduring, and/or permanent. While I am not discounting a temporary loss of ability, this is not the focus of this project, as their short-term problems do not equate to the long term hardships faced by those with disabilities, hard-to-diagnose conditions, and chronic illnesses. In other words, one's fundamental sense of being is not radically altered through minor or temporary loss of ability.

To understand the lived body of the ill/disabled individual, understanding the bodily orders of perception which the body is a subject/object is necessary to comprehend how lived experience translates across first- to third- person experience. This relationship translates directly to the healthcare provider/patient relationship, where the supposedly objective actor is in a complex position of interpreting and acknowledging the communication between themselves and their patient. Such complexity can be analyzed briefly through Jean-Paul Sartre's (1905-1980) three orders of the body. Sartre was one of the key figures in the existentialist movement, with Sartre providing a unique perspective as a phenomenological existentialist.

Healthcare providers are put in the precarious situation of interpreting the patient's body both as objective (its physical, material nature) and the subjective (as determined by the patient's lived, first-person experience) orders. Both affirm each other

to belonging to both orders, giving rise to a third: intersubjectivity. Intersubjectivity is the way by which I experience my body as it is cast back in the experience of it by others. So, when the patient becomes the object in question, their intersubjectivity may be minimized insofar as restoring their body's objective functioning becomes the primary goal. The sense of unease, discomfort, alienation, and self-consciousness that comes with falling ill arises from losing one's sense of subjectivity under the medical gaze, as an objectified patient.

The ill and/or disabled body experiences friction with concepts and expectations of normalcy, such as presumptions of a harmonious relationship of the healthy body to the world. In this sense, the healthy body can be viewed as transparent: it is not experienced explicitly, while still being the means by which one operates within the world; the healthy body experiences the body implicitly, without thematizing it as an object of attention. When something works 'as expected', one does not pay attention to how it functions. Carel (2016) explicates this with reference to the German phenomenologist Martin Heidegger (1917-1976) and his description of the broken tool (59). Thus, when I use a screwdriver, I do not pay attention to it if it is functioning. Counter to the healthy body, the ill body becomes much like a broken tool: taking over one's way of being and consequently restricting one's avenues of action and possibility. The transparent body and the ill body operate on two different planes of being, as serious illness reconstructs the ill person's way of being. The stark contrast between the transparency of the healthy body and body in illness/disability also reinforces one another, as the disappearance of the healthy body is inherently the absence of health; the

body becomes more opaque as its subjectivity is replaced for objective measurements and determinations of its state of being.

As the body is “our general medium for having a world”<sup>14</sup>, such a fundamental disruption to one’s being is a transformative process; experiencing life through the transparent body is both world-shattering and world-making. While I will cover how this process is world-making in the following chapter, for now I would like to focus on how the body in illness experiences a palpable feeling of loss. As the body in illness is a body that is made possible through the absence of objective *health*, a clear determination is drawn of what the body *should* be. Shattering the self-conception of one’s body generates the discomfort in the experiencing the body as opaque under the medical gaze. This can generate a deep sense of loss. The body in illness as world-shattering can present us with a multifaceted loss: loss of one’s health and recognition of bodily transformation, illness as dis-ability, and the internalized social architecture of compulsory able-bodiedness, replaced with a more precarious and uncertain embodiment.

Examining how the lived body changes in illness, we turn to loss of one’s health and bodily transformation. It is useful to turn to S. Kay Toombs (1987) a phenomenologist who herself experiences multiple sclerosis, who has characterized the experience of illness as exhibiting a ‘typical’ way of being.<sup>15</sup> Toombs identifies the following characteristics to be typical of the illness experience: the perception of loss of wholeness, loss of certainty, loss of control, loss of freedom to act, and loss of the

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<sup>14</sup> Merleau-Ponty 2012, *Phenomenology of Perception*. 147 as cited in Carel 34.

<sup>15</sup> Toombs argues that these characteristics are integral to the complex experience of illness, remaining at its core, despite varying empirical features.



familiar world. Toombs begins her analysis with a loss of wholeness, as she states it arises from a sense of bodily impairment. I believe that this is a point of contention in becoming the ill/disabled body: overcoming one's perception of oneself as able-bodied. This characteristic of illness can be the most difficult hurdle after the pervasiveness of compulsory able-bodied values, which have deeply shaped our relationship to our bodies as social beings. When faced with illness, the body can no longer have the same taken-for-grantedness the transparent, healthy body has; the ill body asserts a will that opposes my own. The ill body disrupts the sense of bodily self-unity, with the body in illness experienced as other-than-me. As such, illness is experienced "as a threat to the self, so the loss of integrity is not only of bodily integrity, but also of the integrity of the self." (Toombs 1987, 230; Toombs 1992, p. 90-2 as cited in Carel, 42) As a result of this loss, one surrenders one fundamental assumption: one's indestructability, which causes considerable anxiety and worry. This anxiety is of an existential nature and understanding it as such is crucial as it creates a deep apprehension that is difficult to communicate for the individual experiencing illness. In this sense, illness is experienced as a volatile interruption, "an unexpected mishap in an otherwise carefully crafted life" (ibid). Experiencing illness as such leads to a loss of sense of control. The 'seemingly random unfolding' of one's illness(es) feels more like an incomprehensibly unlucky occurrence - not a set of 'freely chosen life circumstances'. With the familiar world seeming to slip away, the body seems uncontrollable and unpredictable – a heightened "sense of loss of control caused by the realization that the belief that medical science and technology protect us from the vagaries of ill health" becomes one's reality. This is compounded with the ill individual's lack of knowledge in this new realm. Toombs explains that the

lack of ability “to make rational choices is eroded because of [her] lack of medical knowledge and limited ability to judge whether the health professional professing to heal can in fact do so” (Toombs 1987, cited in Carel, *ibid*)

Feeling isolated in the ill body leads to a feeling of the loss of freedom to act. When one is restricted by her lack of medical knowledge, Toombs argues this concurrently restricts her ability to freely choose her course of action. While Toombs uses this in the specific example of choosing one’s medical treatment, this sense of loss extends into the quotidian experience of illness. Doctors and diagnosticians can make changes to one’s treatment plan and provide guidance, but this directly translates to the routines, or habits, of the ill body. Through affecting the body in this manner, illness changes what Merleau-Ponty calls the habitual body. The body’s orientation “towards” the world occurs through the present body (here, Husserl’s “I can”) and through the collection of the body’s previous engagements in past activities that sediment into a general, autonomous character – the habitual body. Informed by the idea that the body participates in spatiality as an intentional “I can”, bodily space is a multilayered phenomenon of relating to things - as such that the body is not “in” a space but rather inhabits it. In illness, the security in the false beliefs of guaranteed health reshapes the habitual body. The habits sedimented as general and autonomous are no longer reliable, as the permanence felt in the perception of one’s body is no longer guaranteed. Such a loss restrains one’s freedom to act in a manner that feels safe, throwing the body into a sense of anxiety and precarity: what experiences will highlight my body’s lack of health, what lifestyle factors could be potentially harmful to one’s general health and/or induce increases in symptoms from illness, and so on. I believe this is of importance to take note

of since most of the literature around illness and disability focuses on the primary aspects of one's medical treatment rather than how these factors of illness radiate into quotidian life. This insight relates to that of queer theory, that "queerness" is about a much wider range of experience than sexuality or "what happens in the bedroom," extending out of the private sphere to shape factors of day-to-day life.

Loss of the freedom to act furthers the existential nature of the body in illness: not only am I restricted by my treatment plan, and the clinicians who have formulated it for me, but I am restricted in my ability to act as a free agent in an environment and society that was constructed for an able-bodied majority that I am not, or no longer, a part of. As such, the result is the fifth form of loss identified by Toombs: loss of the everyday world. In this sense, Toombs is referring to the social existence of the ill individual. Illness interrupts the sense of harmony in bodily unity and a distinct mode of being in the world, leading to the ill person discontinuing 'life as usual'; one can no longer participate in normal activities in the way one used to. As social subjects, much of the world's familiarity comes from its 'sharedness' with others – another loss experienced in illness. This loss shakes the temporal dimension of one's world as plans for one's future must be adjusted according to one's prognosis and treatment plan. As the health of the past is 'broken off' from the ill present, the future itself is suddenly in question, rendered as unknown and potentially inaccessible. Once these elements of being-in-the-world are shattered, the domains identified by Toombs must be intentionally re-evaluated. Regardless of whether these losses are restored, one is left with a sense of uncertainty and fragility.

Now that I have established a basis for a feminist phenomenology of illness, I believe it is of utmost importance to draw clear distinctions between the experiences of disability, chronic illness, and difficult-to-diagnose conditions. While there are overlapping characteristics amongst these categories, I argue that each has factors that must be accounted for when establishing a comprehensive phenomenology of illness which leads to a greater sense of intelligibility for those in question. In the following section, I will expand upon these categories and how they affect the experience of illness amongst expectations of bodily function/dysfunction. In doing so, I will begin to move from the realm of canon, of classical phenomenological methodology, to that of a critical phenomenology of illness.

### **Disability, Hard-To-Diagnose Conditions, and Chronic Illness: Why We Need to Draw a Distinction**

To those who are unfamiliar with the realm of illness and disability, deciphering the differences between these categories may seem simple. The predominant understandings of disability and illness appear succinct, but definitionally these classifications have a fair amount of overlap. Within the chronically ill and disabled community/communities, these definitions are considered more complicated. I argue that a third category, hard-to-diagnose conditions, brings a further nuance to these systems of classification. Through demonstrating these differences, I will argue how these classifications directly translate to how the body experiences non-normate embodiment. These distinctions are critical as they deeply shape the phenomenological experience of

illness and disability. As such, this is where we see a greater need for these types of inquiries as they challenge normative expectations of bodily integrity and wholeness.

Disability, as defined by the Merriam-Webster dictionary, is “a physical, mental, cognitive, or developmental condition that impairs, interferes with, or limits a person’s ability to engage in certain tasks or actions or participate in typical activities and interactions.” When discussing definitions of disability, it is important to note that these can range based off the context. For example, legal definitions such as the definition used for the Americans with Disabilities Act (ADA) or for receiving Social Security Disability related benefits vary. The ADA defines an individual with a disability as someone who has a physical or mental impairment that extensively limits one or more major life activity. This framework also recognizes those who have a record of impairment, even if they are not currently disabled.

Chronic illness, also commonly referred to as chronic disease or chronic conditions in medicine, are “conditions that last a year or more and require ongoing medical attention and/or limit activities of daily living.” This term has a wide variety of meanings, however, depending upon the source utilized. As such, it makes managing these conditions much more difficult. It is conceivable that the recommendations provided for management of a chronic disease are potentially overlooked by the individuals afflicted due to a lack of knowledge. Conversely, said individuals could potentially use recommendations when it may not be advisable to do so.

Disability and chronic illness are defined in such a manner that there is naturally some area for nuanced interpretations of individual cases and the presentation of symptoms. However, this room for nuance can complicate the approach clinicians take.

As medicine seeks to identify objective, measurable bodily dysfunction, more complicated symptoms may not be easily detected by basic tests such as blood draws or X-ray imaging. Without the anecdotal experience of symptoms, and a conviction in one's bodily state in the face of potentially inconclusive testing, the process of diagnosis would begin and end here. Unfortunately, for many experiencing chronic illness, this is the case. Living undiagnosed is a precarious reality, and this brings us to a third classification: hard to diagnose conditions.

The need for this classification originates in the failures of modern medicine's ability to detect and aid those who have bodily dysfunction that needs advanced testing methods, who experience periods of remission where the dysfunction becomes undetectable, and/or require advanced knowledge from specialized diagnosticians that can be difficult to attain due to lack of access (financially or due to high demand for services). While these conditions could be a chronic illness or result in disability, I believe this classification is necessary because this is not the case for all illnesses or disabilities, and because the undiagnosed and/or undiagnosable status of one's concerns specifically tinge this experience, both in relation to medical professionals, family, and friends, and in relation to oneself.

When conditions are hard to diagnose, patients are expected to become not only their own advocates but de facto medical 'experts' in their condition and symptomology. As such, these individuals would highly benefit from a phenomenology of illness. The disjuncture between first- and third- person experience calls for an extensive account of how embodiment undergoes a radical change in illness and disability. The overlapping elements of these categorizations, it should be noted, determine how the experience of

illness effects the existential anxiety faced for the pathologized body. While one may have chronic illness(es) that affect one's health, these conditions do not have to necessarily be disabling. Conversely, chronic illness(es) may also have a disabling effect if they affect one's ability to perform day-to-day tasks. Disability, on the other hand, has the guaranteed element of affecting one's ability to perform one or more daily tasks, in this context, generally without the possibility of remission.

Hard to diagnose conditions may overlap with either the disability or chronic illness, but the embodiment they experience can be more complex. While these conditions may not necessarily be a rare disease/condition, nonetheless the experience of this embodiment and seeking treatment is complicated. Without access to the care and clinicians required to identify and manage these impairments, many of these individuals are left without adequate treatment and therefore a lesser quality of life. This is where the quality of life arguments has failed disabled and chronically ill individuals: having these conditions does not necessarily equate to a lesser quality of life, but lack of access to the medical care one needs does. As such, those with hard to diagnose are left in the precarious situation of trying to maintain some level of homeostasis while the body becomes an unknown, anxiety ridden object awaiting proper treatment. In the following section, I will explore how these classifications and the disjuncture between patient testimony and clinician assessment operate in the real world. Utilizing the documentary series *Diagnosis*, I will use the personal accounts of two young women struggling to seek a diagnosis for their own rare conditions. In doing so, it will become clear how this process needs a greater understanding between the first- and third- person experience of illness in the sphere of medicine and in everyday life.

## Case Studies: Diagnosis

Case studies, while not necessarily providing a phenomenological account, aid in understanding how first- and third- person experience in exchanges with clinicians and diagnosticians. While providing a complex more in-depth account of how case studies and phenomenology are linked in a meaningful way would be of value, unfortunately it is beyond the scope of this project. However, one can utilize the studies to demonstrate the accounts of an individual's experience and the third-person perspective in action.

The Netflix documentary series *Diagnosis* follows Dr. Lisa Sanders as she brings her New York Times column, under the same title, to life. Following individuals with mysterious symptoms, Dr. Sanders follows and aids in these individuals seeking a diagnosis with the assistance of crowd sourcing. With clinicians and diagnosticians perplexed by these individual cases, crowd sourcing gives the individuals in question a larger pool of resources to draw from. Because the people on this series are experiencing hard to diagnose conditions, using their anecdotal accounts of their lived experiences of illness brings greater clarity to non-normate embodiment. In this following section, I will follow the stories of Angel and Lashay as they seek a diagnosis for their own hard to diagnose conditions. After outlining each study, I will analyze how these cases are similar in many aspects but also demonstrate the need for a phenomenology of illness in the real world.

In episode one, the viewer encounters a young woman named Angel Parker. With her symptoms beginning at the age fourteen, by twenty-three these symptoms have



severely limited her ability to exercise<sup>16</sup>, work, or perform some essential daily activities.

As the symptoms have persisted and intensified over the course of nine years, Angel experiences excruciating daily pain that begins in her legs and goes up to her jaw.

Clinicians and diagnosticians did not know how to control her pain, despite Angel's ability to communicate the intense feelings of pain she experiences:

It's basically just like a super ache with someone squeezing on you at the same time, so like your muscles can't really breathe. I can't move, can't walk, sometimes can't talk. I've had a seizure, and they think it's because of it. When I go to the restroom, my urine is black. It looks like coffee grounds. Every time I walk into a doctor's office, they say, "Well, yeah, you really are a mystery."  
("Detective Work")

Knowing her case is complicated, Angel recalls receiving a lot of answers like the one above. Their statements had no 'but', no comma, no 'maybe' – leaving Angel in the position of not knowing, 'the scariest thing in the world': "I can deal with the pain, I can still live, but not knowing is what's holding me back." ("Detective Work")

During her flare ups, Angel's Creatine Kinase (CK) levels skyrocket to such an extreme that she requires hospitalization. Within the body, her muscles are leaking protein into her bloodstream. At their highest, Angel's CK levels reached 57,000 – with the level for 'safe' release from the hospital being 1,000. The lack of answers has not only effected Angel's health, but has plunged her into medical debt, with three doctors suing her over payment at the time of filming. With no answers and previous doctors chasing Angel for money, her parents do not know how to help their daughter – and it's

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<sup>16</sup> Angel had been a very athletic individual before the serious onset of illness, going to the gym up to five times a week. At the time of filming, she was struggling to go on a long-distance walk, which led to her hospitalization.

clearly exasperating. Upon meeting Angel's father, Ray, he reflects while looking at some older photos of his daughter:

That's when she was normal, okay? And then, what was it, seventh grade all this crap started?... You get to the point where you think that, you know, well maybe the doctors are like, "Well, I don't know what it is, so I really don't care," and that's aggravating, you know what I mean? That's my baby girl. And I'm like after 10, 11 years, whatever it's been, you know, "Come on, give us something." ("Deductive Work")

Feeling unsure of how her future will unravel, facing feelings of uncertainty in the experience of illness, Angel initially reports that she cannot see a future with children – something she wants for both herself and her boyfriend, Mac – if her health continues to deteriorate. Faced with the news, Angel's parents become incensed. Ray expresses his disappointment through his own frustration of feeling 'robbed' of grandchildren. While this is a bit overdramatic, as Angel is not the couple's only child of reproductive age, she makes it noticeably clear that without an answer, she won't have kids – 'it isn't fair'.<sup>17</sup>

Dr. Sanders, when coming across Angel's case, uses her column and a new online video resource to crowd source potential diagnoses. Focusing specifically on disorders that cause the destruction of muscle, which causes the muscular pain, Angel and Dr. Sanders identify three diagnoses that seem most probable: Metabolic Myopathies, McArdle's Disease, or CPT2 Disease. Of the three, Angel leans more towards McArdle's and CPT2, having a 'strong feeling' it could be these while voicing disappointment with the fact that the disorder is likely genetic.

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<sup>17</sup> While these thoughts are valid for the chronically ill and/or disabled person in question, as only they know the specific embodiment of their symptomology, this statement also reflects a commonly held and deeply engrained ableist belief that those with disabilities and chronic illnesses have a poor quality of life.

With more responses trickling in as the article remained online, the team heard from an Italian medical student named Marta Busso. Busso was currently working on a thesis in metabolic diseases and had recommendations for specific metabolic testing to find Angel's diagnosis. The school she attends, a pediatric center that specializes on genetic disorders, would be willing to perform the tests if Angel can come to them. As taxpayers pay for the public healthcare system in Italy due to their more socialist approach to medicine, Angel will not have to pay for any of the testing performed. Having already filed for bankruptcy, and unable to take on more medical debt, Angel and Mac go to Turin, Italy, to meet with the team at Regina Margherita Hospital.

After running a panel of 100 metabolic and genetic disorders, all the markers for metabolic diseases came back negative. Waiting for the genetic results dampened Angel's spirits, as the hope for a diagnosis was diminishing after the results from the metabolic disorders panels. Upon receiving the genetic testing results, Angel did find the name of her disorder: CPT2 Disease. For this condition, a new diet regimen will be enough to manage symptoms through increasing sugar intake and decreasing fatty acid consumption. Although the genetics team did recommend Mac receive a full genetics panel, they assured the couple that Angel is in fact okay to have children. Now, all thanks to one medical student in Italy, and Angel is 'a completely different person': validated, assured in her ability to have a future, and ready to proceed with the proper treatment for her condition.

Being led to the solution, however, is not a linear process for all the patients featured on *Diagnosis*. In episode five, we meet Lashay a young woman whose symptoms have perplexed doctors. When asked what is happening, Lashay states:

My body is doing through something no one can really figure out. Like after I eat or... I don't know why but it just turns my stomach in a way where I just can't handle it. Ever since this has started. I haven't kept fluids down. All the doctors said, like, "I want you on a feeding tube," but I'm kind of, I still want control over like, what I eat. I still wanna eat. I still wanna have that. And so whenever I throw up, I keep on eating just so I can get some calories in and have something in my stomach. ("A Question of Trust")

For the past two years, this has been Lashay's life. The genesis of the problem seems to be linked to a raccoon bite Lashay got while on a family vacation to Costa Rica. After returning home, Lashay began experiencing vomiting, headache, neck pain, and stomach pain. While Dr. Sanders believes the trauma of the event could be affecting her, there is most likely an underlying physiological dysfunction driving Lashay's symptoms.

Since the trip to Costa Rica, Lashay's life has drastically changed: "When I eat, it's hard for me to move around. I can be hunched over, like, for three hours, and I have really sensitive eyes. I can't handle light very well. In ways, it feels like my head is literally about to explode." ("A Question of Trust") With her abilities to participate in the public world diminishing, Lashay has had to remain at home and tries to come in to school whenever she feels well enough so she can keep on track. Prior to her illness, Lashay had a lot of friends. These friends were lost when she got sick, leading Lashay to feel isolated – "The worst part about this is I can't have the connections I wish I could with people." ("A Question of Trust")

Clinicians were making these feelings of loss more intense. After Lashay was initially admitted to the hospital, the doctor working on her case told her that her symptoms were 'all in her head' and she was 'doing it to herself'; writing Lashay's physical dysfunction off as psychological. Growing distrustful of the medical

establishment, Lashay's parents have become incredibly protective and in control of her treatment. As Lashay suffers from chronic dehydration from her vomiting spells, she has had a port inserted for easier rehydration. This port comes with serious risks, which has been cause for concern amongst the doctors who are treating Lashay at the time of filming. If an infection of the area were to ever occur, the proximity to Lashay's heart could be fatal.

Unfortunately for Lashay, the crowd sourcing endeavor turned overwhelmingly sour from negative assumptions of young women and eating disorders; based off her age and sex, many individuals disregarded Lashay as being bulimic. The voices of the crowd were not all negative and passive, bringing up a few likely diagnoses for Lashay to explore. One issue, leakage of cerebral spinal fluids, could be the cause of the heads and lightheadedness. This option had been explored by the family, going as far as trying the blood patch treatment for this possibility. However, with the procedure only having a thirty-percent success rate and Lashay experiencing severe back pain after the procedure, Lashay's parents are unwilling to try this procedure again despite the pleas of her doctor that this treatment could still work. Since the symptoms originated with a raccoon bite, parasitic infections had also been mentioned as a possibility but had already been ruled out by Lashay's medical treatment at the onset of her illness. Another suggestion was for a form of autonomic dysfunction called Postural Orthostatic Tachycardia Syndrome (POTS). Dealing with issues of circulation and blood stroke, this disorder could be the genesis of Lashay's headaches, light sensitivity, brain fog, nausea, and vomiting. Again, this option was explored by Lashay's medical team and she did not respond to the

medications for POTS management. With all other suggestions exhausted, one option remained promising: Rumination Syndrome.

A rare, chronic problem, Rumination Syndrome is a functional issue between the brain and guts' communication with one another. This diagnosis had been on the family's radar previously – upon Lashay's second trip to the emergency room, the possibility had been presented to the family but 'it wasn't presented right'. When faced with individuals who also had Rumination Syndrome, Lashay began to show a restrained interest in exploring treatment further. Yet, Lashay's mother again controlled Lashay's course of treatment through her hesitancy and inaction. Caught up on the 'why' of what is happening, Lashay's mother's defensive reactions and caution could be actively harming her daughter's help. Through focusing on her own concerns, such as her daughter's ability to have kids – a statement which caught Lashay, still a teenager, off – Lashay's mom's priorities aren't honed in on getting Lashay the treatment she needs; losing herself in the larger picture of how Lashay's life could be radically changed, she fails to take immediate action to help her in the present. Despite looking into and speaking with a patient at the Columbus Nationwide Hospital, as of the time of filming Lashay has not sought treatment for her likely Rumination Syndrome.

The cases of Angel and Lashay have a few things in common. Both individuals are young women of reproductive age, adding more weight to their diagnosis process. While Angel willingly state that she eventually wants to be a mother, for Lashay it is presumed based off her biological sex and her parent's wishes for grandchildren. Pairing reproductive futurity with a feeling of uncertainty in illness, these young women are left not only negotiating how to manage their health but also the health of a non-existent child

that they are already being held responsible for. Facing rare and chronic problems, both women are (luckily) dealing with disorders that can be managed through habit modifications. And, most strikingly, both women experienced a disconnectedness between their lived experiences in illness and the clinicians and diagnosticians' interpretations of their symptomologies and reasonings in seeking treatment.

Although Angel and Lashay varying outcomes with the crowd-sourcing method Dr. Sanders employed, these stories originate in the disjuncture between first- and third-person experience. Experiencing complex symptoms with no discernable origin, the only truly reliable perceptions of the phenomenon of illness lie within the testimonial account of the condition. Objective, measurable data – at least what the clinicians had attempted – did not give them an easily achieved diagnosis, therefore the clinicians who were trained to trust the data met the women in question with a confused shrug, or a shrug off. But, as was demonstrated in both cases, by broadening the resources available to these women they were brought closer, if not to, a diagnosis. Such an experiment is successful because, although there are background facts added for readers to hypothesize, these stories rely on the anecdotal to appeal to readers' sense of empathy. Removed from the sterile hallways of a medical center, readers who come across the cases in the *Diagnosis* column are making a deliberate decision to interact with these individuals who would otherwise be 'just another story' to quickly glance over.

The show *Diagnosis* demonstrates in real time how this disjuncture operates in patients' quotidian existence. While not expressed in phenomenological terms, one can see how the perceptions of illness and loss take place in each patient. Case studies such as these make explicit the concepts a phenomenology of illness calls for in making the

perceived realities of illness accessible to those without the expertise in engaging in these recollections and conversations. As this project is informed by values that welcome accessible resources, it is also of important to recognize that much of academic scholarship can be inaccessible to those dealing with disabilities and chronic illnesses for a variety of reasons. My hope is that I have outlined a need for a phenomenology of illness that accounts for the first-person experience of illness as world-shattering, as patients deal with the loss of their transparent body, undergo existential anxiety, and embark on the process of seeking treatment in a manner that both does justice to the principles it draws from while making this knowledge accessible to as many readers as possible.

In the next chapter, I will expand upon what it is like to experience the ‘abnormal’ embodiment in illness from my own perspective. I will draw upon how negotiating the space of seeking a diagnosis can be world-making rather than simply world-shattering. Informed by the process of seeking my own diagnosis, I will uncover how this break between first- and third- person experience operates maliciously under testimonial injustice. Here, we will see how a phenomenology of illness is in nature an exercise of critical phenomenology: exploring the perceptions of individuals while keeping their identities in mind.



### **Chapter III**

#### **The Lived Experience of Epistemic Injustice, Diagnosis, and Difficult to Diagnose Conditions**

As my first two chapters have demonstrated, the results of engaging in both 1) a feminist theory and 2) a phenomenology of illness bring forth new possibilities for making the lived experiences of those with difficult-to-diagnose, chronic conditions to light. This project takes on personal stakes. As a young woman who appears to be able-bodied, I lacked the language to make my lived experience intelligible to the able-bodied world, and consequently, the medical establishment. My experience of embodiment was incomprehensible to strangers and doctors, a woman in her early twenties in so much pain that she needed to rely on a cane- yet test after test came back normal. Repeatedly, my experiences defied their expectations of an average woman. As I have shown, such expectations of normality and embodiment are deeply entrenched in how we interact with other subjects, specifically when we determine if their testimony and experiences are credible. This affects one's ability to navigate institutional medicine, and the ability to advocate for oneself. Testimonial injustice accounts for a part of this phenomenon, discounting groups as knowers and purveyors of knowledge<sup>18</sup>. People put in the precarious position of needing to prove themselves are at the mercy of the subject's they

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<sup>18</sup> Fricker, Amanda. *Epistemic Injustice: Power & the Ethics of Knowing*. 1

are interacting with, specifically when factors of sex, disability, race, and so on, enter the picture.

Within the realm of hard-to-diagnose, chronic illness and disability, this experience can be transformed through obtaining a diagnosis. Diagnosis names the phenomena experienced through the physical experience of disorder, and as illness, the lived experience of living as such. Yet, the basic understanding of obtaining a diagnosis, understood as obtaining an answer to attain treatment, is too reductive. Dialogue around diagnosis is complex, and I will be approaching the subject with the assistance of Jennifer Scuro's 2017 monograph, *Addressing Ableism: Philosophical Questions Via Disability Studies*. While I largely agree with Scuro's analysis, my thinking diverges when it comes to the "handing off" or being "handed" a diagnosis. While Scuro focuses on the third person, world-shattering aspects of being handed a diagnosis affectively, I am focusing on the world-creating aspects. As I note in what follows, this has in part to do with the experiences of diagnosis that each of us negotiate: Scuro is responding to her eldest daughter's diagnosis with autism<sup>19</sup>, whereas my chronic, hard-to-diagnose experiences take up a different, more enabling relationship to diagnosis. While this process can be filled with ableist assumptions and disablist practices, I argue that naming the unnamed is not always a negative experience, despite the ableist framing under which medicine all too often operates. Rather, I argue that diagnosis is not an end-destination, but a road of transformation. Receiving a diagnosis is merely the beginning to a new way of being:

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<sup>19</sup> In making this analysis, Scuro is not saying that autism itself is harmful. Scuro is formulating a philosophical analysis, through the third person perspective and affective experience, that interrogates the ableist attitudes of healthcare professionals, educators, and so on, in 'being handed' a diagnosis and consequently receiving negative attitudes and perceptions towards her daughter.

being in illness, being in dis-ability, being in pain. Diagnosis reconstructs one's sense of self, and how one relates to one's body and the world. This approach recognizes ableism and its precarious nature, while empowering those who have been plagued by misdiagnosis and nondiagnosis in their search for a diagnostic answer.

As the cases studies in my second chapter have demonstrated, there is recognition in diagnosis. To further this line of thought, and in the spirit of a phenomenology of illness valuing the personal and anecdotal, I will provide a brief account for my own experience with a hard-to-diagnose condition, Ehlers Danlos Syndrome (EDS). If we are to transform the way we, as a society, engage with those with hard-to-diagnose conditions, chronic illnesses, and disabilities, the testimony of these individuals must be taken seriously in order to make a world in which is more inclusive. While disability exists on a spectrum, with many variants of physiological 'dysfunctionality', I specifically am focusing on the experiences of those who have hard-to-diagnose conditions and the difficulty of navigating they gray space between the able-bodied and disabled worlds. I believe this area of disability and illness need further investigation, and this is my contribution to that effort by sharing my own experiences with a hard to diagnose condition. To do so, I will employ a phenomenology of falling to demonstrate an experience of illness and bodily vulnerability.

To conclude, I will address the precarity of being disabled, having a hard to diagnose condition, or chronically ill. Faced with ableist beliefs of low quality of life, these individuals face the violent reality of a eugenic hope for their existence to be eradicated. This hope is misinformed, as the able-bodied majority lacks the understanding

of the ill and disabled experience. In calling for a feminist phenomenology of illness, we must assess and transform that which we cannot accept.

### **Normality and Expectations of Embodiment**

As I have demonstrated throughout this project, dominant concepts of normality deeply shape how we perceive subjects and their experiences. As such, normality deeply construes how we perceive persons as pathologized subjects. Medical authorities, such as the doctors one relies on to take one's testimony to actionable points, operate under this same premise. Ableism, as I have stated, is a quasi-transcendental structure that not only structures forms of oppression, but the very structures of consciousness that inform one's being-in-the-world. Inevitably, the normative expectations of compulsory able-bodiedness and the ableist conflation of disabled and chronically ill persons are foundational to how medicine operates. As previously stated, the ableist conflation states that disability is a lack or deprivation, and this deprivation of potential goods is a harm. Harm causes and/or is a form of pain and suffering, and therefore given these three claims, disability is coextensive with or causes pain and suffering. As such, expert diagnosticians can fuel ableist attitudes and sociocultural assumptions.

Relying heavily on the dichotomy of normal/abnormal, medicine expects subject-objects to fit neatly into two categories: those with physiological dysfunction (disease), and those who do not- those who are "normal". Biotechnologies have advanced this imperative through diagnostic testing plus bureaucratic standards and obstacles to navigating medicine as an individual with a chronic health problem. While biotechnologies can test for the data a doctor believes is necessary or sufficient to find the

cause of a patient's symptoms, they are seldom a space for patient advocacy. Perceptions of symptomology are highly perceptive to ableist interpretations, shaping the diagnostic testing performed. In other words, such means are restricted to the recommendation's doctors make, which are not always reflective of the symptom's patients state they experience. If medicine is to subscribe to the sociocultural idea that compulsory able-bodiedness is to be expected, one experiencing chronic symptoms undiagnosed has to navigate a complicated path of diagnostic testing, therapies, and specialists required to potentially receive an answer to some of their most pressing needs. Years can be wasted in the steps required to prove the validity of one's symptoms through diagnostic means because, many times, doctors fail to see the full picture provided through patients' testimonies.

For example, medical students have been told for decades that, 'When you hear hoofbeats behind you, don't expect to see a zebra.' Put differently, look for the more common diagnosis, not the more surprising, rare diagnosis. In response, much of the rare disease community, including the EDS community, have adopted the mantra, 'Sometimes when you hear hoofbeats, it really is a zebra.' Responding in this manner has direct stakes in the fact that reaching a diagnosis for a rare disease is difficult at best, and potentially a life-long and unfruitful process at worst. Again, much of this relates back to education, since those who specialize in rare diseases and conditions are a minority of the doctors who go through the medical academy and are less accessible to the public; therefore, patients are left competing for the attention and treatment of a very select group of physicians. I would like to reiterate that this is only if one can gain access to them; many of these physicians provide services that are astronomically expensive within

the U.S. medical system, even for individuals with top health insurance coverage. Furthermore, many of these more niche specialists require pre-requisite testing and treatment from other specialists before they will take an appointment, providing another barrier in the form of time and money. This causally relates back to the neoliberal and capitalist influences of labor power and economic return, as these factors shape the bureaucratic practices followed by the medical establishment and medical insurance companies.

I can speak to this from personal experience. While I have experienced symptoms of EDS and its comorbidities for my entire life, these symptoms started to more concretely manifest at the age of fourteen. This is when I began my journey down the diagnostic rabbit hole, not knowing that it would take an entire decade for the process to truly bear any concrete answers. While my symptoms got progressively worse as my comorbidities strengthened and my connective tissue started to weaken, the subsequent pain became a continual reminder that something was deeply wrong with my body. At the age of twenty-two, the pain became overtly intense and constant, and I came to the realization that I could no longer handle walking unaided. The searing, deep pain radiating from (primarily) my sacroiliac joints was compromising my ability to keep a consistent, steady gait without losing my balance, feeling my joints slipping, and experiencing the feeling of the stiff feedback my muscles gave, struggling to keep me upright and moving. I had to make the choice to start using a cane out of necessity, yet my choice was interpreted differently. Upon getting the first appointment I could with a doctor at my primary physician's office, my account was immediately degraded to psychosomatic causes. The young, male doctor I met (I will refer to this man as Dr. W),

who asked about my symptoms and medical history, brushed off everything I said to him. He immediately suggested that I see a psychiatrist, that I must have some unprocessed trauma that is manifesting into *my belief* that I was in severe pain.

I kept coming up against the same obstacle, regardless of which doctor I visited: no one would take my account seriously. Doctors before this previous instance had invalidated my experience, had told me to “take a Tylenol and get over it”, but I truly believed that the sight of a young woman desperate for relief from the constant pain she was experiencing, using a cane, would change things. But it did not. If anything, it truly demonstrated that until a test came back proving there was some type of physiological ‘dysfunction’, that I would never have my experiences taken seriously. This was both soul-crushing, but highly motivating: I knew there was something wrong, and I began demanding answers and asserting myself in a way that I never could have without this realization. And this approach became fruitful: within a year of my appointment with Dr. W, I finally received a diagnosis. But this simple fact must be reiterated: it took an entire decade to get to the point of diagnosis. The roadblocks I faced throughout those ten years was based off of the fact that I was perceived as too young to be claiming the pain and symptoms I was feeling, and much of my treatment relied on having other figures of authority , such as my able-bodied mother, there to validate my experiences. In other words, my testimony about my health and well-being was not viewed as credible, and therefore another individual with able-bodied privilege needed to be in the room for the doctor to even consider listening to the experiences I was facing.

This constant need to prove oneself, and the discounting of the lived experiences of individuals who are perceived as having less than credible personal accounts, is what

Miranda Fricker (2007) describes as epistemic injustice. Put differently, epistemic injustice occurs “when prejudice causes a hearer to give a deflated level of credibility to a speaker’s word” (1). Epistemic injustice must be considered congruently with hermeneutical injustice, which occurs “at a prior stage, when a gap in collective interpretative resources puts someone at an unfair disadvantage when it comes to making sense of their social experiences” (ibid). Testimonial injustice could be said to cause prejudice in the economy of credibility, while hermeneutical injustice is structural prejudice within the economy of collective hermeneutical resources.

Practices of epistemic injustice commonly occur when one is of a marginalized identity, or in other words, not belonging to the dominant identity of white, cis, heterosexual, able-bodied maleness. Connecting back to Young’s “Five Faces of Oppression,” many marginalized communities are demonized for their perceived “dependency,” which is devalued by the hegemonic ideal of ‘pulling yourself up by the bootstraps’ and individual perseverance. Being viewed as a dependent lead to a devaluation of the individual in question, as they are unable to be self-sufficient within the hegemonic framework. Without these dependency frameworks, these individuals, such as the disabled, are left marginalized and powerless.

Once factors such as disability, sex, gender, and race are present, common conceptions of normality and embodiment work against the testimonies provided by these individuals. This directly relates back to the fact that persons with varying marginal identities are allocated to “different” – read “lesser than” – ideals of corporeal specificity that relegates these individuals to lacking the cognitive abilities and social skills to interact with the world as a being-in-the-world. Informed and enforced through able-



bodied cultural imperialism, this ideology permeates the very consciousness of individuals and how we interact with one another. Summarized, hermeneutical injustice is embedded into the dominant culture's psyche and therefore epistemic justice is permissible based upon scrutiny of marginalized individual's cognitive ability and a perceived lack of ability to advocate for oneself in a fruitful manner.

Testimonial injustice, a second form of epistemic injustice on Fricker's account, deeply affects the disabled and chronically ill community. As previously stated, doctors are trained from day one to look for the most likely diagnoses. Unfortunately, when one does not fit neatly into these diagnoses, much of the time medicine will leave you behind. As I have experienced, and as Angel and Lashay demonstrated through their stories in *Diagnosis*, when doctors cannot find the genesis of one's symptoms, if the doctor runs out of steps for the typical-diagnosis path, then one is simply left with the answer of "I don't know" and/or that the causes are psychosomatic in nature: "it's all in your head". Anecdotal accounts are not the only thing stating this; there is also empirical data showing that those experiencing chronic conditions, such as chronic pain, are less likely to receive the treatment that they are seeking. Such a common occurrence is allowed simply because, in the instance of females seeking medical treatment for pain relief, doctors state or simply believe that women are more willing to report their symptoms, and when they do, they tend to *over* exaggerate them. Ideas of hysterical women—that women are just emotional and do not want to get better—inform such beliefs and have done so since the nineteenth century.

Hysteria, however, has been recorded since 1900 BCE through Egyptian depictions of a menstrual abnormalities in women, with the word originating in Greek

from the word ‘uterus’. While initially described as a physiological condition, and formally identified in modern medicine by Jean-Martin Charcot as an unknown internal injury of the nervous system, one of his pupils took this idea to a more perverse end. Sigmund Freud was a student of Charcot and interpreted this data to be a link to be ‘a psychological scar produced through trauma or repression’. Writing these theories from 1880-1915, Freud’s approach to psychoanalysis and hysteria deeply informed how clinicians approached women and their pain. While the scope of this project cannot explore the nuances of how Freudian psychoanalysis has shaped the cultural conception of the female psyche, this is one moment in a longer historical account of the invalidation of women’s pain and lived experiences when they seek medical treatment.

This reality comes into sharp relief to the belief that men are more stoic than women, who are less emotional, so when they state they are in pain they are to be taken seriously. However, the opposite is true. While studies have shown that women report pain more frequently than men, women should be taken seriously when complaints of high, chronic pain are reported. Women are more likely to develop many of the chronic conditions associated with chronic pain: only 10% of those with fibromyalgia are men, among those who have EDS 70% are women versus 30% men, and of all Myalgic Encephalomyelitis (ME)/Chronic Fatigue Syndrome (CFS) patients, approximately 35%-40% are men. While there are an abundant number of disorders that could be investigated based on gender breakdowns, many chronic pain afflictions point to the fact that women disproportionately experience these types of ailments.<sup>20</sup> Yet, despite this well-established

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<sup>20</sup> Other ailments more commonly associated with women include but are not limited to: migraine and chronic tension-type headache, irritable bowel syndrome, temporomandibular disorders, and interstitial cystitis.

knowledge, women of all backgrounds continue to face testimonial disenfranchisement within the medical establishment.

Despite these many barriers, both in the form of medical bureaucratic procedures and hermeneutical/epistemic injustice, one may, with much persistence, ultimately arrive at a diagnosis. While hermeneutical injustice may inform the structural experiences of all, diversity in the medical field and empathetic practices do exist – if in small numbers. Those with more varied life experiences, despite their economic privilege and power, are still informed by how society views all subjects. After my experience with Dr. W, I made a point to reach out to female-identified practitioners in my quest to attain a diagnosis. I have a deep conviction that this is a factor in receiving a diagnosis so quickly, within one year, after struggling to be heard for the previous nine years. And while these individuals are not immune from ableist ideas or disablist practices, I have found their ability to listen to my experiences of chronic illness and pain to have a more profound impact on my diagnosis and treatment. While epistemic injustice can potentially be avoided based up on the individuals one chooses in to interact with, the barriers to diagnosis presented by hermeneutical injustice must be addressed in order to create a truly equitable medical system for all individuals.

## **Diagnosis**

Diagnosis, defined by Oxford Dictionary as “the act of discovering or identifying the exact cause of an illness or a problem”, is a more complicated process than simply consulting with a diagnostician, running a few tests, and receiving a diagnostic answer. If

one's case is not cut and dry, if one doesn't 'check all the boxes', the process becomes much more complicated. Jennifer Scuro (2017) reflects on the process of reaching a diagnosis, and I will be using her line of reasoning to assist in thinking through diagnosis phenomenologically.

As Scuro conceptualizes it, "Diagnoses name bodies and conditions; a diagnosis can excite concern, solicitude, grief, pity, and fear" (21). In the 'handing over' of a diagnosis by a clinician, Scuro found these exchanges to be steeped in judgement, power, and uncontested ableism (21). The phenomenon of being 'handed' a diagnosis could be interpreted as a transfer of negative affect as the patient is faced with the anxiety of the imperatives of able-bodiedness. Regardless of the perspective held by the diagnostician, the issue remains of the reading of individual lives through their symptomology, attaching insufficient language to the 'handing over' of the diagnoses – biasing the expectations and outcomes of the exchanges between patients and doctors. Those in the position to 'hand over' a diagnosis are only tasked with the classification of cases within the taxonomy of known illnesses and disabilities, while they should be focusing on providing a more empathetic approach to treatment. This approach is primarily centered around the world-shattering aspects of diagnosis. Again, this is centered around the fact the Scuro's account of diagnosis is shaped through her third person account of her eldest daughter being diagnosed with autism. But while I focused on the world-shattering aspects of illness previously in chapter 2, in this section I will focus on how receiving a diagnosis can be world-making.<sup>21</sup>

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<sup>21</sup> This does not mean that all of those with disabilities and chronic illnesses experience a sense of world-making in receiving a diagnosis. However, when focusing on those with

Receiving a diagnosis was life changing for me. It was the validation I had been seeking for a decade to a state of being that I had been unable to articulate. Yes, I do appear to be able-bodied, and most of my tests came back normal, but it was all because *we had not been looking in the right place*. My symptoms were being caused by an underlying genetic defect, caused by my body's inability to produce the protein Collagen. This consequently affected all my connective tissues, resulting in my symptoms and various comorbid conditions that I am still getting tested for and managing to this day. However, to understand the impact diagnosis has on an individual, we must develop a more nuanced perspective of what diagnosis is.

Diagnosis is not an end-destination, but rather a road of transformation. Receiving a diagnosis is merely the beginning to a new way of being: being in illness, being in disability, being in pain. Diagnosis reconstructs one's sense of self, and how one relates to one's body and the world. One component, the most focused on during discussions of illness and disability on medicine, is management of the condition(s). This involves, but is not limited to, maintenance in the form of repetitive doctor and specialist visits to consult with a medical team, lifestyle changes such as adopting an exercise regimen or changing one's diet, adaptations such as braces, mobility devices, or other assistive technologies, and mindset changes to adapt to living in a world created for the able-bodied by the able-bodied. While these skills can be learned from a medical team, much of the psychological work and acceptance comes from within. And yes, one can go to a therapist to develop coping strategies and talk through the difficulties of obtaining a

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hard to diagnose conditions, we must consider how the act of receiving a diagnosis is a form of validation and recognition of one's embodiment.

diagnosis and maintaining a chronically ill/disabled body, this is a continual process that doesn't stop once you leave a professional's office.

Reshaping the way one perceives one's self is not an immediate process. Ideas internalized by cultural imperialism, and consequently compulsory able-bodiedness, are deeply engrained due to ableism's quasi-transcendental nature. Learning acceptance and critically questioning ableist assumptions of what the body should be, how it should operate, requires internal reflection that is dependent on an individual's need for acceptance with oneself. Philosophy of disability and phenomenologies of illness are a mode by which one can do so, making intelligible the experiences chronically ill and disabled persons face through their diagnostic journey and throughout their lives. I found much of the language I needed through these means, opening the doors to others whose experiences may have differed from mine in type/quality of diagnosis but through the shared phenomenon of ableism. Understanding concepts such as ableism, dis-ability, the disorder/illness distinction, and hegemonic power structures, to name a few, developed a language that makes what I experience as a disabled person with a hard-to-diagnose condition intelligible to my doctors, my loved ones, and in my interactions with strangers.

In the following section, I will begin to outline a phenomenology of falling.

Falling, in this context, is not simply losing one's footing. Within this context, falling is a direct result of the onset of the symptoms of Postural Orthostatic Tachycardia Syndrome, or POTS, a common comorbidity of EDS. A form of Dysautonomia, dysfunction of the autonomic nervous system, POTS is most commonly a form of orthostatic intolerance.<sup>22</sup>

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<sup>22</sup> Keeping this in mind, there are three primary forms of POTS: Neuropathic POTS, Hyperadrenergic POTS, and Low Blood Volume POTS.

In cases of severe aggravation of symptoms, one's heart rate and blood pressure cannot be regulated and may result in syncope episodes. Common symptoms include, but are not limited to, lightheadedness, rapid heartbeat, dizziness, high/low blood pressure, high/low heart rate, and so on.

But, why falling? Falling is a common symptom experienced by those facing illness, losing a sense of homeostasis and stability. A lack of proprioception and coordination, factors which are affected in the ill and disabled body, makes falling a more common potentiality for these individuals versus the able-bodied individual. On its face, falling seems like a common occurrence for individuals: children, those participating in sports, the elderly. While potential consequences for these falls remain for the above categorizations of persons, for the ill and/or disabled individual it is a reflection upon losing the transparent body and a reminder that their body is facing some form of dysfunction.

### **A Phenomenology of Falling: Experiencing a Near Syncope Episode**

Sinking. This is how a syncope episode begins. Trapped in the sensation of beginning to black out, you feel your heart begin to race. You feel yourself begin to fill with fear: fear of the uncertainty of what is about to occur, questioning your body, fearing if you will be safe if something does happen. No matter how many times this occurs, even in its less severe forms, the phenomenon is nonetheless an experience of fear. Your fear, your body's response to this fight-or-flight situation, reinforces the underlying

feelings of bodily uncertainty: this phenomenon can happen suddenly, and all one is left to do is react.

You are faced with the world shrinking around you. As black static begins to drift into your field of vision, it quickly overcomes your ability to see. This sensation cannot be compared to a mere dizzy spell; unless you have experienced a near-syncope or syncope episode, you cannot understand the experience. Blinded by your own body's inability to maintain homeostasis, you are left scared and in the dark: experiencing the intensity of your body desperately trying to regulate your heart rate and blood pressure, while other bodily functions begin to malfunction. Perhaps this time you will vomit or uncontrollably gag until you wish that you would so the overwhelming sensation of a hot, burning pit in your stomach would cease. Or maybe this time you will lose control over your bladder, unwillingly urinating on yourself. The attack of symptoms in this rapid manner is such a shock to the autonomic nervous system that the nature of what is happening is difficult to comprehend to the person experiencing it.

With your body struggling to maintain homeostasis, all the functions one can normally rely on the autonomic nervous system to regulate become a source of anxiety: breathing, heart rate, blood pressure, being able to control one's bladder and bowels. I am unsure as to what will dysfunction as I am falling, who might see me, and what shame may consequently ensue in being caught in one of my body's most vulnerable moments. This experience, while available to some, does not affect them in the same manner that it affects the individual with a pre-existing condition that predisposes them to syncope episodes. There is a precariousness to living life with a predisposition to syncope: your world is shrunk to encompass the activities and spaces that feel 'safe'. Of course, the



feeling of safety is no guarantee – many factors affect when and why someone experiences a syncope episode, which vastly limits one’s ability to operate in a world that is hazardous to one’s health.

The act of falling itself, in syncope, presents its own health risk. Unable to control the fall, you cannot prepare your body for impact or adjust the fall to avoid bodily injury. Broken bones, dislocated joints, severe swelling and/or bruising, and soft tissue injuries are all possibilities. You have no control over what is happening, no matter how much you struggle to get your body under control. The lack of sense of control permeates into everyday life, unsure when your body will be unable to function and could collapse. The shrinking of one’s possibilities and sense of uncertainty in the body lead to a continual feeling of loss – when experiencing chronic illness, you never know when a flare up will occur that may be unmanageable for the patient.

Experiencing a syncope or near-syncope episode unveils the fragility of one’s body. When conditions are unmanaged or severe, one lives in a constant state of anxiety. The world is no longer familiar, no longer reliable. One day you may be able to walk up a few flights of stairs, the next you need to sit down on the steps or landing to take a break from the overwhelming sensation of your heart pounding and your body beginning to overheat. If you do not drink enough water and consume enough electrolytes, you will become more prone to an episode. One has to manage their tasks down to the hour: when should I take my prescriptions, when do I take my salt pills, how many small meals do I need to eat to avoid aggravating my heart condition. The freedom to act spontaneously is lost due to the risks it could present to one’s health. The ability to act in the public realm becomes a source of anxiety. What if the space isn’t accessible and I need to walk up the

stairs, what if it's too hot outside and I cannot regulate my body temperature, what if I don't have access to water to take my medications? There are so many factors and questions one must access themselves and access in order to make decisions that could otherwise compromise their health.

'Coming to' comes with the realization of the lack of transparency of the ill body. My health condition(s) have been made explicit: there is no hiding or denying a syncope episode from those who watched you experience it. Discomfort, generally rising from ideas of compulsory able-bodiedness that are shattered in these moments of bodily weakness, can lead to a deep feeling of shame for the individual experiencing the syncope episode. This feeling is an example of the transfer of negative affect. While this link between affect theory and disability has been investigated by theorists such as Scuro within the realm of 'being handed' a diagnosis, I argue that being caught in a moment of bodily vulnerability carries its own transfer of negative affect. Witnessing another's body functionally begin to fail forces those who encounter these scenarios to realize the true weakness of the body: it is a feeling of deep discomfort, as one does not know what is happening and most often the onlookers of the event do not know how to adequately help the ill person. The person experiencing the syncope episode is not only caught in their vulnerability but faced with the explicit discomfort of those around them. While further investigation of this transfer of negative affect would be of value to understanding the feelings of anxiety and shame that come with illness, it is beyond the scope of this paper at the present time.

Recovering from the episode, you feel exhausted and overwhelmed. The episode can cause a feeling of sensory overstimulation: the light is now blinding, the feeling of

clothing rubbing against your skin is overwhelming, and as your sense of hearing returns, the world goes from muted to full volume in an instant. Realizing what has happened, you need to take a quick assessment of your body. Where is the pain coming from now, how severe is it, do I need to seek immediate medical attention? What else happened as I struggled to maintain consciousness: are my pants visibly soiled, or did I vomit (maybe even on myself)? Where is my blood pressure monitor, my water bottle, salt pills? Can I drive myself home, or do I need someone to come and pick me up? As these questions race through your head, you are simultaneously processing the anxiety and shame around being caught in a syncope episode. While asking yourself these questions, you are concurrently processing how the episode appeared to those viewing it. Did someone witness my bladder dysfunction as I began to fall? Am I about to have a very uncomfortable conversation about my health conditions to ease the tension of able-bodied persons – information that I do not need to disclose but will make the situation more understandable to the viewer(s).

Relying deeply on empathy from others, these conversations can be generative to help able-bodied persons understand bodily vulnerability. However, much of the understanding of disability and disability advocacy is placed upon disabled persons, providing the burden of constantly explaining their lived experiences to those who hold common misconceptions of what disabled experience is like. We perform this labor by making our lived experiences intelligible to able-bodied persons. In doing so, we hope that they will abandon the hegemonic ideals of compulsory able-bodiedness and develop a greater understanding of the experiences of disability and illness – as one in four

Americans have a disability (CDC 2018), it is likely they know someone or will themselves become disabled at some point.

### **Precarity in Illness and Disability: Conclusion**

A reoccurring theme in the experience of illness is a sense of overall precarity. As I have covered, this precarity originates in the loss of the transparent body and the subsequently mentioned five losses Toombs identifies in illness. However, this precarity is more nuanced. The very existence of disabled and ill persons is precarious, as ableist fantasies of a more utopian world wish to eradicate disability, chronic illnesses, and hard to diagnose conditions.

The predominant belief that disabled and ill persons have a poorer quality of life is the genesis of this belief. While it is inherently a eugenic belief, holding that persons with these qualities should not exist, it is widely held as an ideal that medicine can eventually lead us to. Idealizing those who have the transparent body, with a taken-for-grantedness for health, eliminates the ability for those with different embodiments to be understood in their full personhood. Reduction of the individual to the bodily dysfunction or impairment disqualifies the testimonies of the experiences of their own lives.

This idea that we can “fix” and prevent disabilities originates in a sense of hopefulness, albeit misguided. Hopefulness, in this sense, is an important concept as it challenges perceptions of the ‘future’ tense. Opting to ‘cure’ disability and illness follows ideological ableist formulations of what the body should be. Here, being disabled “destabilizes the future tense for some more than others, rendering some lives more precarious than others, stealing the hope that comes from having been a “person in the

world” to the status of a non-person, closer to pethood in that someone has to “claim” you, “own” you, or “represent” your interests.” (Scuro 107)<sup>23</sup> The desire to fix here is paternalistic in nature, as it values stasis and security, while rejecting those who fail to meet such expectations.

As such, disability advocates fight against the conditions which make the lives of the disabled and chronically ill precarious. Through working together, the community actively works against the facets of oppression identified by Young in Chapter 1. Living a life of marginalization and oppression based off one’s identity is unacceptable no matter the circumstance, but particularly when the individuals in question are also facing hegemonic ideals that believe the world would be better off without disability and illness, and henceforth their existence.

This brings us to a call to action; to have a more equitable society, we must identify our societal biases towards marginalized persons and our perceptions of their experiences. Hence why a phenomenology of illness would specifically aid in addressing these societal inequities faced by the disabled and chronically ill. As our experiences as disabled and chronically ill persons are full of insight into what health and bodily function can be, we are in the unique position to provide an understanding of the body’s vulnerability to those who take their health, generally, for granted.

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<sup>23</sup> While autistic advocates have challenged the way that parents deem themselves as having total epistemic authority to speak for these individuals, Scuro addresses this in her unease to take up disabled spaces and narratives as an individual who does not have access to these experiences first hand. Identifying herself as disabled, Scuro recognizes the precarious nature of speaking for others in a broad and sweeping manner while also tackling the issues of ableism from a philosophical perspective.

A critical phenomenology of illness is committed to the anecdotal accounts and perceptions of those who cannot bracket these experiences as they fundamentally shape their ability to 'be' in the world. The disjuncture between the experiences of those with disabilities, hard to diagnose conditions, and chronic illnesses and how they are perceived by others demonstrates a need for a method to synthesize the first- and third- person experience of illness and disability. Through phenomenological concepts, one can clarify their everyday experiences in illness in a manner that breaks down these experiences into a comprehensible account of the experience itself. In doing so, one can elucidate the realities of their conditions to achieve a better course of treatment and/or diagnosis and prove that despite the dominant conception that these dysfunctions affect one's quality of life, this is not necessarily the case. While the feelings towards a decreased quality of life varies from patient to patient, in whole these feelings originate in the body being observed as a measure, opaque object rather than an intersubjective being.

Many of the quality of life arguments are focused on hegemonic ideals of bodily stability and certainty, and therefore this ideology devalues abnormality in the body. The devaluing patients experience by physicians, nursing aids, insurance agents, and by ableist individuals is the true genesis of a poorer quality-of-life. These individuals shape how medicine and society perceives and adapts to those who have disabilities and chronic illnesses. As such, this affects how built environments in the public sphere can accommodate those with non-normate embodiments. As we can see, this all has a domino effect: because we fundamentally do not understand the experience of disability and illness, we further marginalize and oppress these individuals by making social structures and environments that are inhospitable to them.

In performing this analysis, I hope to have laid out a foundation to the importance of employing a phenomenology of illness to better understand the experiences of those living with non-normate embodiments. This analysis is by no means finished, as there are many areas of the experience of illness that are worthy of exploration: illness and its relationship as being-towards-death, can an individual(s) have a true quality of life in illness, what is the philosophical role of illness? While these are all questions of deep importance to this project, it is simply beyond its scope. However, with the basic phenomenological concepts employed in this project, I hope to have demonstrated how this methodology can create a better world for those living with disability, hard to diagnose conditions, and chronic illnesses while making this material accessible to the everyday reader. As a society, we desperately need to tackle with these inequities that oppress and marginalize those who do not fit in to the hegemonic ideals of ‘normality’. In doing so, we further our mission for a more equitable society for all – no matter one’s social identity.

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