UNDERSTANDING DISABILITY BY BECOMING DISABLED: AN AUTOETHNOGRPAHY OF A STROKE SURVIOR

by

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In this autoethnographic study, I explore my personal journey as a 39-year-old stroke survivor, examining the intersection of disability, identity, and social interactions. Through my lived experience, I investigate how a sudden transition from a non-disabled to disabled status impacted my sense of self and daily life. My research reveals three key themes: loss of agency, identity transformation, and the intersectional role of disability in social assumptions and interactions. Drawing from disability studies and curriculum studies frameworks, I analyze my experiences in healthcare settings, public spaces, and social interactions to understand the complex interplay between disability, age, and social constructs. My findings highlight significant gaps in age-appropriate resources for young stroke survivors and demonstrate the need for enhanced cultural competency among healthcare providers. This study contributes to both disability studies and curriculum studies by offering insights into embodied learning experiences and challenging traditional notions of disability.

Keywords: autoethnography, disability studies, stroke survivor, embodied learning, identity transformation, young adult disability, healthcare interactions, cultural competency, curriculum studies, lived experience

Chapter One: Introduction

Eleven years ago, I went to bed a non-disabled individual. When I woke up the next morning, my body and life as I had once known was slowly changing, impacted by a stroke that I had sometime in the night. I was 39 years old and at a point in life when I was single, living independently, self-sufficient, energetic, and socially active. My stroke changed every aspect of my pre-stroke life. I spent six months in a rehabilitation hospital relearning to walk, dress, and talk again. At this rehabilitation hospital, healthcare workers treated me differently, which made me uncomfortable, and I was curious to understand why. Looking back on this life-changing experience, I saw that I was still the same person; the only difference was that I was now disabled. Did this new identity of disability equate to different treatments? I knew little of the disability culture but already experienced different treatment since becoming disabled. What's wrong with disability? I set out to uncover how to be disabled and what this new identity meant for me. I unfortunately found no information on the experiences of young stroke survivors, which brings the urgency of my study and the contributions it may bring into Curriculum Studies, my field of study, and into Disability Studies.

To help me explore this, I wanted an approach to research and writing that would best describe and allow me to write a personal account in understanding my experiences of my post-stroke and new disability identity. To accomplish this, I felt an autoethnography would best meet my needs. Autoethnography's focus on the interconnectedness of inner and outer realities, with personal experience at its core, makes it particularly effective for communicating disabled embodiment (Adams, Holman Jones, and Ellis, 2015). It creates a space to untangle the complex relationships between a disabled body and a world not designed for it, revealing experiences of the physical body, the external world, and the fit—or misfit—between them. As

Marks (1999) notes, it is a method that "recognizes the importance of examining the interrelationship between embodied subjects and complex social and psychic relationships" (ix). Autoethnographies give disabled authors tools to voice nuanced narratives of their embodied experiences.

The central question of this autoethnography is: What impact did my stroke have on my self-identity? Sub-questions of this research include: How did my dual experience as a non-disabled person prior to my stroke impact my experiences as a person with a disability after it? More specifically, how did I come to understand the privilege associated with being a non-disabled individual while I came to terms with my disability? How does a curriculum studies framework help in understanding my recovery and disability?

Background

A stroke, also known as a cerebrovascular accident (CVA), occurs when blood flow to the brain is interrupted, causing brain cells to die. According to the American Stroke Association, stroke is a significant cause of disability worldwide. It is estimated that stroke is the fifth leading cause of death and a leading cause of disability in the United States. Stroke can result in physical, cognitive, and emotional disabilities that can impact a person's daily life and ability to work. Symptoms of a stroke can vary depending on the severity and location of the brain damage, which causes different disabilities depending on the area of the brain that has been damaged. The type of stroke I had was a dissection of the right carotid artery (weakened artery that became loose in a coughing fit), which was basically a cerebral infarction, or an ischemic stroke that caused a blood clot affecting my right frontal cortex of the brain. This blood clot damaged the area of my brain that controls the left side of my body, rendering the left side paralyzed. I also suffered from what is known as post-stroke spasticity (PSS), which is a condition in which muscles stiffen or tighten, preventing fluid motion; more specifically, my left arm was contorted upward with my fist in a ball looking as if I was carrying a tray, and my left foot no longer was flat but now curved, which made walking difficult. With the use of a walking brace, I can now walk but with a limp. My PSS also brought on a condition called clonus reflex, which causes large, noticeable movements caused by the neurological cell and nerve brain damage and leads to muscle tightness and pain. What I found interesting is that before my stroke, I had a loud, outspoken, gregarious personality, but after my stroke, I had a calmer and quieter demeanor, perhaps from exhaustion or medication. This experience was devastating, but over time, I have been able to accommodate my disability and work through the difficulty it has caused. Strokes are commonly misunderstood as a disease that only affects the older population. However, there are various factors associated with strokes, such as gender, implications of sex as biological characteristics that have led to younger women experiencing strokes, the types of strokes that are common in younger women like me, and age-related factors for stroke patients. While strokes in younger patients are less common than in older adults, they are recently on the rise because of risk factors like migraines, pregnancy, and substance use. Because of the randomness of disability, a stroke brings on and the recent increase of younger stroke survivors, there are notable gaps in research regarding younger stroke survivors' experiences. Because of the lack of research on the experiences of young stroke survivors, I often referenced my past intrepid self to assist me in navigating this new disability culture and landscape.

Purpose of the Study

I want my autoethnographic research to help me understand unique ways of thinking and feeling that will help me make sense of my interactions with others, particularly in the presence of power relations. I want to see how my lived experience intertwines with physical experiences and social interactions that will connect me to broader contexts. I found that the two theoretical fields of Disability Studies and Curriculum Studies would provide such a platform. I decided that I should first start with *currere* before I move into the autoethnographic stage of my research. This curriculum theory-informed process of narration becomes a vehicle for understanding the nature of the self. Pinar's (1975) concept of currere, or "curriculum of life," seemed to be a natural fit with the storytelling traditions of autoethnography. Whereas currere examines an individual's perspective on a reflection of an experience to better understand the lived experience as a curriculum by engaging in one's past, present and future academic endeavors. Autoethnography extends currere by employing the researcher's individual voice in dialogue and their own lived experiences as the primary data source, providing insights into cultural contexts. Currere will provide a strategy for me to better understand my past, present, and future experiences as I embody these understandings and apply them toward my experience of the disability culture and my place among it.

Significance of the Study

Overall, I felt that Disability Studies and Curriculum Studies through currere and autoethnography would best capture some of the sophisticated ways in which bodies, knowledge, and lived experience can merge, which can later be viewed as a platform to engage with. Because essentially, they are all connected as vehicles for understanding the nature of the self and the experience of understanding and interpreting it.

Theoretical Framework

Disability Studies

First-wave Disability Studies established the factors that led to the structural, economic, and cultural exclusion of people with sensory, physical, and cognitive impairments in the last century. The politicization of disabled people is at the heart of these developments. Disability Studies has entered a host of training and educational contexts, social policies, legislative discourses, and professional practices. Furthermore, Disability Studies has been allied with many theoretical ideas.

For Shakespeare (1996), questions of disability identity bridge key contemporary debates, including the structure/agency problem and the biology/society dualism. In his chapter "Exploring the Divide," he proposes several ways to examine these issues by charting a new path through these dichotomies. Identity is a complex field, and scholars across various disciplines use the term differently within social sciences and social theories. Shakespeare (1996) identifies two main approaches to categorizing disabled people as a group: one based on a physical or medical understanding. The first approach conceives disability as the outcome of biological determinism, focusing on physical differences. It defines disabled people as those whose bodies do not work, look different, act differently, or cannot do productive work. This analysis centers on performance and conformity, raising questions of normality by assuming a standard from which disabled people deviate. The second approach views disability as a cultural category with a socio-cultural understanding that views disability as an outcome of social processes and as a constructed category. For Shakespeare (1996), self-identity can be viewed through two lenses: the medical approach and the social approach. The medical approach sees identity as an outcome of physical impairment, focusing on adjustment, mourning, and coming to terms with loss. In contrast, the social approach considers identity as shaped by oppressive social relations, emphasizing societal change, empowerment of disabled people, and promoting a different self-understanding. Giddens (1991) summarizes this approach to self-identity: "Self-identity is not a distinctive trait, or even a collection of traits possessed by the individual. It is the self as reflexively understood by the person in terms of her or his biography" (p. 53). Identity thus connects the social and personal, involving individuals placing themselves in a collective context. Giddens (1991) further emphasizes that "A person's identity is not to be found in behavior nor—important though this is—in the reaction of others, but in the capacity to keep a particular narrative going" (p. 54).

Disabled people, amidst political and social gains, continue to experience discrimination in multiple areas. While disability has been theorized as an experience-based identity (Gill, 1997; Linton, 1998; Putnam, 2005), Disability Studies has also explored how disability as a set of meanings influences, and even *structures,* social relationships both through and beyond personal experiences of disability (Davis, 1995; Kafer, 2013; Rogers & Blue Swadener, 2001; Snyder & Mitchell, 2006; Thomas, 2004). One important example of this move is the development of the concept of ableism, or the compulsory preference for non-disability (Campbell, 2009). These attitudes can both contribute to prejudice and reflect internalization of society's prejudices because of specific stereotypes and social norms related to disability that can manifest in various ways, including biased language, exclusionary attitudes, harmful policies, and restrictive practices.

Both disability studies and critical disability studies examine disability as a social construct, by exploring the experiences of disabled people, and advocating for their rights and inclusion, but critical disability studies goes beyond simply describing disability to critically analyze its social, cultural, and political construction. It questions how disability is represented, experienced, and used to shape power dynamics and social structures.

The development of the concept of ableism, or the compulsory preference for non-disability, can be seen in the start of the second wave of Disability Studies (Campbell, 2009).

Ableism, like other "isms" such as racism and sexism, describes discrimination towards a social group, in this case disabled people, but it also describes how certain ideals and attributes are valued or not valued (Wolbring, 2008). For example, walking is more socially valued than moving by way of wheelchair (Hehir, 2007). Disabled people have expressed that the negative effects of ableism have been socially and psychologically damaging to them in several ways (Bell, 2013; Campbell, 2008; Keller & Galgay, 2010; Ostrove & Crawford, 2006; Overboe, 1999; Palombi, 2012). Explicit (conscious) and implicit (unconscious) attitudes should be explored because people may feel pressure to conceal their explicit biases or may be unaware that they hold biases (Amodio & Mendoza, 2011; Antonak & Livneh, 2000). Implicit attitudes function as a stigma through social interactions and relate to external cues and learned associations (Amodio & Mendoza, 2011). As such, they can contribute to prejudice and reflect internalization of society's prejudices. There is a particular need to explore implicit attitudes in the case of disability because of specific stereotypes and social norms related to disability. The ideology of ability is powerful in that it is rooted in our everyday actions, thoughts, judgment, and intention. For Sieber (2013), in its most radical form, the ideology of ability defines the baseline by which humanness is determined, setting the measure of the body and mind that gives or denies human status to individual persons, which in turn affects our judgments, definitions, and values about all human beings by creating ideals that are discriminatory and exclusionary. These ideals can create social locations outside of and critical of its purview in the perspective of disability.

Critical Disability Studies, then, capture some of the sophisticated ways in which bodies, knowledge, and lived experience can merge, which might be viewed then, following Scott Lash, as a lifted-out space: a platform or plateau through which to think through, act, resist, relate, communicate, and engage with one another against the hybridized forms of oppression and discrimination that so often do not speak singularly of disability. Discrimination is an increasingly complicated entanglement of disability, gender, sexuality, nation, ethnicity, age, and class. Critical disability studies have developed theories that are in concert with contemporary lives, the complexities of alienation, and rich hopes of resistance. Hence, critical disability studies and disability studies are both fields of scholarship that concern themselves with the representation of disability across social, cultural, historical, and political contexts. In many ways, similarities might be drawn between the project of disability studies and other social theories of human difference, such as gender studies or race/ethnicity studies (Ferguson & Nusbaum, 2012). In this way, critical disability theory is an emancipatory and developing discourse (Goodley, Liddiard, & Runswick Cole 2018: 206; Meekosha & Shuttleworth 2009: 48). Thinkers use the method to both describe the socio-political constructions of disability and track the impacts of these constructions on oppressed persons, including but not limited to those to whom the concept "disability" attaches. Complicating this expansive approach, accountability to disabled persons is paramount to this work. Erevelles (2014) find that not "everyone is disabled" but prefer historically embedded materialist accounts of disability at intersections among multiple categories of analysis, including "race, class, gender, nation, and sexual identity" (p. 219).They both refuse a “fixed definition” of disability and prefer leaving the boundaries of the concept of disability open and not settling on who counts as disabled. Moreover, it is through exploring the heritage and construction of the disability identity, and when that identity is in flux with multiple categories, that we understand how they are related to the very nature of human embodiment. The disability identity needs increased knowledge in the awareness of its different kinds, values, and realities.

Critical disability studies pluralize models for thinking about disability, while scholars examine how non-disabled ideologies emerge in and through representation, and how such representations result in a culture of ableism that invalidates disabled experiences. Critical disability studies build upon the insights that challenge capitalist conditions of alienation and acknowledge that we are living in a time of complex identity politics, of debates around the ethics of care, political and theoretical appeals to the significance of the body, and what counts as disabled. This provided a framework for me to better understand and address ethical issues related to disability by highlighting the importance of relationships, interdependence, and relational responsibility. It acknowledges the inherent value of individuals with disabilities and recognizes their needs for support and care, while also emphasizing the reciprocal nature of caregiving and the importance of promoting autonomy and self-determination. Here, I saw and learned that identities are formed through relationships and these individuals are interconnected and interdependent. People with disabilities often rely on others for support and care. Autonomy is often valued in ethical frameworks, the ethic of care recognizes that autonomy can be a complex and contested concept, especially for people with disabilities. It acknowledges the potential limitations of focusing solely on individual autonomy and advocates for a more relational understanding of autonomy that includes the support and care provided by others. For me, I was able experience a form of autonomy when I reached out for support from others.

Curriculum Studies and Curriculum Theory

Curriculum studies is a concentration within curriculum and instruction concerned with understanding curricula as an active force of human educational experience. During the late 1960s, this field endured a reconceptualization, in which the field moved away from matters of prescriptive planning for instruction toward an attempt to better understand the process of schooling from a wide variety of perspectives, including experiences as curriculum making and meaning (Pinar, Reynolds, Slattery, & Taubman, 1995/2008; Schubert, Lopez Schubert, Thomas, & Carroll, 2002). This reconceptualization brought about new uses of autobiography, self-narration, storytelling, and personal voice. Through the use of autobiography in contemporary curriculum studies scholarship, especially if connections were made to the use of storytelling, narrative, and intimacy (Clandinin & Connelly, 2000; He & Phillion, 2008), personal voice (Grumet, 1990; Miller, 2005, 1990), or the significance of personal space and place (Kincheloe & Pinar, 1991; Reynolds 2013, 2014; Whitlock, 2007). Currere has evolved from the meaning of "the running of the metaphor" to "the path followed. The method of currere was first proposed by Pinar in 1975, which refers to a process of introspective inquiry that "provides a strategy for students of curriculum to study the relations between academic knowledge and life history in the interests of self-understanding and social reconstruction" (Pinar, 2012, p. 44). Currere is an attempt to reclaim education as a journey toward self-understanding or an understanding of self as it is always in relation to other selves and always positioned in the world at a particular historical moment. The use of autobiography and autoethnography expands the currere process by recognizing that different kinds of people possess different assumptions about the world—a multitude of ways of speaking, writing, valuing, and believing. Schiro (2012) used the concepts of ideology, philosophy, belief, vision, and perspectives while referring to the terminology of curriculum theory. He used curriculum ideology instead of the concept of curriculum theory and explained the word ideology that he used intensively as "a community of ideas, a comprehensive view, a way of looking at things or a world view that represents people or a group who believe the way that the world should be organized and function" (p. 10).

Methodology Overview

Autoethnographic Approach

Autoethnography as a method participates in the ongoing social construction of research norms and practices while it seeks to influence the social construction of specific phenomena. The methodological tenets of autoethnography include using personal experience as the primary data source, deep self-reflection (reflexivity), linking personal experiences to broader cultural contexts, employing evocative narrative presentation, and acknowledging the researcher's subjective position within the study; essentially, exploring one's own lived experiences to analyze and critique cultural norms and practices through a deeply personal lens. Autoethnography involves several core components that distinguish it as a qualitative methodology. These key elements include a focus on personal experience, the researcher as subject, reflexivity, evocative narrative presentation, and linking the personal to broader cultural contexts (Jones, Adams, & Ellis, 2013).

Autoethnographers must be visible in their work, reflect on personal experiences, engage with readers, and evoke emotional responses in readers. Autoethnographers also need to analyze the story and connect it to relevant literature; that is, the text should demonstrate "knowledge of past research on a topic" (Jones, Adams, & Ellis, 2013, p. 23) and make a substantive contribution to the field of social science research (Bochner, 2000; Richardson, 2000a; Richardson, 2000b). This contribution should offer something new or a new angle to existing research (Ellis, 2009).

Currere method and Autoethnography

Pinar's (1975) concept of currere, or "curriculum of life," seemed to be a natural fit with the storytelling traditions of autoethnography mentioned above. Whereas currere examined an individual's perspective on a concept, autoethnography extended currere by employing the individual voice in dialogue. Moreover, currere was a strategy that examined an individual's perspective on a concept, and autoethnography extended currere by exploring how life histories affected the meanings they gave to experiences in a social and cultural context.

Currere allowed me to turn inward and examine my experiences, toward a deeper understanding of myself and my outer world. I used this method to travel into the past to reexamine my memories of the post-stroke experiences in the rehabilitation hospital where I stayed for six months and noticed a change in my treatment. Pinar (1975) posited, "currere is a reflective cycle in which thought bends back upon itself and thus recovers its volition" (p. 517). With this idea in place, the question of self-renewal was associated with a heightened consciousness and cultural revolution, with a shift from outer to inner by exploring a systematic search of our inner experiences and our use of the public world. Examining the public world's materials and our uses of them through their structures, designs, and evaluation had great potential. This process disclosed new structures by bringing to the surface assumptions and awareness of the experiences by naming the old assumptions. Pinar's idea was to step back and peer into the darkness by exploring the blind spots through a series of four steps or stages: "regressive, progressive, analytical, and synthetical." The regressive stage was to return to the past, walk around and observe your past lived experience, record what was observed, and by recording this observation, bring this process into the present. In the progressive stage, the student of currere brought what was revealed from the past into the present while projecting these experiences into potential future scenarios. In the analytical stage, the student of currere put the knowledge gained in the regressive and progressive stages aside to find the connections and themes that had emerged. In the synthetical stage, the student of currere collected all the insights from the first three stages—the "regressive, progressive, and analytical"—to create a collective whole. In this stage, the student of currere looked for common themes or categories and within such themes focused on the self and point of view. The student of currere was encouraged to take their point of view, examine it, and juxtapose its relation to one's psychological, physical, and biographic conditions (both public and private).

Data Collection and Analysis Methods

The currere process provided a strategy that allowed me to re-experience or re-remember older memories of conversations that I had with people about stroke and disability. I used these older memories for my autoethnographic data. I wrote down my thoughts, feelings, and observations, which included significant moments, emotions, and insights in a reflexive journal I kept. This journal ensured a thorough account of past events, reliving past experiences and examining them from a present perspective. In my journal, I documented my observations and interactions that were relevant to my experiences, which included details about the environment, conversations, and my own reactions by first writing the narrative with dialogues within each snapshot memory, then provided an extended and detailed context to memory. I then looked for patterns and themes. Next, I analyzed my situation/topic and explored the root cause, giving insights into my interpretation. I documented my biases, assumptions, and made notes of them in a reflective journal for my interpretation. I used my reflexive journal to record the data gained from my self-interview with my currere notes as a self-interview. Anderson and Glass-Coffin (2013) suggested constructing a "dialogue between one's past and present selves" through a self-interview by reconstructing "scenes from one's own life experiences" (p. 69). The self-interview allowed me to examine my two selves—pre-stroke and post-stroke. Data came from my recorded observations, interactions, and a self-interview that were written and recorded in my reflexive journal. I approached my experience analytically by first separating the findings into smaller topics, then tried to understand the cause-effect relationships between variables and answering questions of why and how. I used descriptive coding by assigning bolded statements to sections of my experiences to capture the important nuances of my experiences in a four-step process:

1. Read the data and identified the topics that surfaced.
2. Create codes for each topic.
3. Code excerpts according to topic.
4. Collect all the excerpts together that are related to each descriptive code.

This approach involved carefully reading my work to identify meaningful fragments. I then reviewed these fragments to develop a categorization scheme. For my coding process, I used inductive coding.

Overview of Chapters

Chapter Two is a Literature Review where I present past studies to inform, guide, reference, and give contextual information for my autoethnographic study on my post-stroke experience. I designed this literature review around relevant themes, such as post-stroke experience, disability, and ability. I utilize the concepts and aspects of this literature review to organize this inquiry along a landscape that locates my topic of study within the general contexts of curriculum making, educational experience, and aspects of my own learning, epistemology, and environment to contextualize my own experiences of my post-stroke embodiment.

Chapter Three is my Methodology section where I explore the methodological framework and approach of autoethnography, with a particular focus on its application in disability studies. The discussion begins by establishing the epistemological foundation, rooted in social constructivism, which underpins the research. This paradigm views knowledge and reality as products of social interaction, providing a lens through which to examine societal attitudes towards disability. The chapter then delves into my positionality, emphasizing the importance of transparency and reflexivity in autoethnographic research. It outlines the key principles and methods of autoethnography, highlighting its unique characteristics as a qualitative, self-focused, and context-conscious research method.

Chapter Four is my findings and analysis where I start by describing the morning my stroke began and then expand on the two currere experiences at the rehabilitation hospital. Following this, I move into the snapshot memories. In each snapshot memory, I used narrative storytelling to create vivid descriptions of my personal experiences so that I could connect to broader cultural, political, and social meanings and understandings.

Chapter Five is my discussion and implications where I offer a deeper understanding of the disability experience as I step back to view the broader picture as my narratives reveal how everyday interactions elucidate personal experiences about stroke, disability, adaptation, social understanding, and societal attitudes.

Chapter 2: Literature Review

In the following section, I present past studies to inform, guide, reference, and give contextual information for my autoethnographic study on my post-stroke experience. I designed this literature review around relevant themes, such as post-stroke experience, disability, and ability. I utilize the concepts and aspects of this literature review to organize this inquiry along a landscape that locates my topic of study within the general contexts of curriculum making, educational experience, and aspects of my own learning, epistemology, and environment to contextualize my own experiences of my post-stroke embodiment.

Factors in Post-Stroke Experience

This section explores the various factors associated with strokes, such as gender, implications of sex as the biological characteristics that has led to younger women experiencing strokes, and the types of strokes that are common in younger women like me, and age-related factors for stroke patients. There are factors of race, and socioeconomic factors that impact stroke recovery. Comparing these studies to my own realities helped me to better understand my experiences, and my new identity.

Women's Experience with Strokes

Kari Kvigne (2004) conducted a phenomenological study on 25 first-time stroke survivors—all women—from three rehabilitation hospitals in Norway. The study involved three in-depth, semi-structured interviews: the first in the hospital six weeks post-stroke, and the second and third in the participants' homes at six months and one-year post-stroke, respectively. These interviews explored women's experiences before and after their strokes, their hopes for the future, and their recovery expectations. The interview schedule was designed to gain insight into the women's experiences during different rehabilitation phases and their projections for post-stroke life. The researchers recorded and transcribed the interviews, bracketing preconceptions and prior theoretical understandings. They then broke down the material into meaning units to identify similarities and differences among participants. Finally, they generated themes from the women's experiences, basing their interpretations on phenomenological and feminist perspectives.

A common theme emerged among these women: a struggle to maintain familiar ways of life and preserve their sense of self, closely tied to valued roles as mothers, wives, grandmothers, and homemakers. While striving for these roles, the women also grappled with depression and fatigue. The study highlighted how female stroke survivors sought to maintain and control their valued feminine roles. One participant, Sofia, a 37-year-old mother of three—closely mirrored tmy post-stroke experience. Paralyzed on one side of her body, Sofia struggled to return to her pre-stroke life of work and daily activities. She poignantly expressed, "Sometimes I was totally worn out. The only thing I wanted was to lie down and cry. But one cannot give up; you must keep doing the things that are needed" (p. 379). This study illuminated the intense struggle women face in preserving their sense of self after a stroke.

The Impact of Sex and Gender on Stroke

Rexrode, Madsen, Yu, Lichtman, and Miller (2022) reviewed literature on the impact of sex and gender on stroke. Defining sex as the biological characteristics of individuals including genetic, biologic, and physiological expression. Defining gender as a social construct that includes gender identity, expression, roles, and stereotypes for female, male, and gender diverse people. Gender also relates to power, economic resources, and health care access, all of which can also influence health (p.512). In this review, Rexrode et al. (2022) discussed that women are living longer than men and showed that "older women have a risk of stroke is higher for women than men, with a 1 in 4 risk of stroke for women after age 25" (p.513). The change in stroke risk with age varied by sex; stroke incidence is higher in women than men for those older than 30.

According to Rexrode et al. (2022) stroke was the second leading cause of death worldwide, as well as the second cause of disability-adjusted life-years (p.512). In the United States in 2019, stroke was the third leading cause of death in women, compared with fifth in men. Women accounted for 57.1% of stroke deaths in 2019, with stroke accounting for 6.2% of all female deaths, while comprising 4.4% of all male deaths (p.513). In the United States, the lifetime risk of stroke is higher in women (20%–21%) than in men (14%–17%), for a 55-year-old individual.

Women are more likely to have cardiovascular disease and atrial fibrillation, whereas in men, coronary heart disease is more common. There are also female-specific risk factors like reproductive life span that are less directly modifiable but potentially important for risk prediction. For example, the use of oral contraceptive pills is associated with stroke in young women. There are also adverse pregnancy outcomes, that include: preterm delivery, gestational hypertension, preeclampsia, and fetal growth restriction, which have been consistently associated with increased long-term risk of cardiovascular disease increases the risk of stroke in the mother. Older women that are undertaking menopausal hormone therapy, have shown an increase in ischemic strokes among women taking oral menopausal hormone therapy. Because women experience hormonal implication differently, they are more likely to experience a stroke.

Regarding women's post-stroke experience Rexrode et al. (2022) found that women have poorer functional recovery and lower quality of life after stroke for women compared with men. The social context for women who experience stroke was also different as well. Age at onset of stroke is on average 4 to 6 years older in women than men. Moreover, women are more likely to be widowed, unmarried, or living alone and have a higher degree of disability in their activities of daily living than men at the time of their stroke. (p 513).

According to Rexrode et al. (2022) depression was common following a stroke, affecting up to one-third of stroke survivors. Across the adult life span, depression is nearly twice as common in women than men. Studies have found a higher prevalence of poststroke depression in women than men. A systematic review of the prevalence of poststroke depression(PSD) in 45 publications between 1982 and 2006 found the prevalence of PSD was 78% higher among women as compared with men. "Women remained significantly more likely to have higher prevalence, incidence, or increased number of symptoms of depression than men after multivariable adjustment for factors such as age, stroke severity, and activity limitation" (Rexrode et al., 2022, p.522).

Rexrode et al. (2022) found that women's sex places them are at a higher risk factor of stroke when compared to men and have higher mortality rates. Women also had a higher degree of disability in their post-stroke activities while having higher degrees of depression.

Experiences of Stroke in Younger Women

Tarihoran, Honey, & Slark, J. (2023) conducted a study to explore the experiences of younger women who have had a stroke to understand their experiences and support needs. The authors used data from the world stroke organization global stroke fact sheet of 2022 and found that the stroke incidence for women (6.4 million) exceeded that of men (5.8 million), like the trends in stroke prevalence between women (56.4 million) and men (45.0 million), with most of these people residing in low to middle-income countries (Tarihoran, et al.2023, p.2). Therefore, Tarihoran et al. (2023) wanted to understand women's stroke experience, and focus on their perceived burdens and support needs, which may aid in future stroke management guidelines and better after-stroke care strategies. The authors found that recent statistics showed the incidence of any stroke in the young adult has increased by twenty three percent in the last decade, contrasting with rates in older adults, which have decreased 11% including other past studies like how a US study found that before 44 years of age, women had a higher stroke incidence than men, which aligned with a Netherlands study that found that women between 18 and 44 years old have more strokes than males. In Canada, stroke incidence in women under 30 is increased compared to men (Tarihoran, et al.,2023. p.2).

This study used a qualitative description approach, developed by Sandelowski (2000), that recruited eligible women from Aotearoa New Zealand's public and private organizations and through existing stroke-community networks that offered various support services, which cater to the Māori and Pa Pacific people of this area and are substantially more likely than people of European ethnicity to have a stroke. An email invitation to participate was distributed. This study used a snowball recruitment method, where those who received the email was asked to forward the message to others who might wish to participate. Eligible focus group participants had to be women with a past or current stroke diagnosis, and who were aged 18 to 64 years when they experienced their stroke. Five women who had experienced a stroke and were eligible, agreed to join one focus group interview, which consisted of an interview held at a convenient time and location for participants, and all were offered the opportunity to join in person or via videoconferencing (Zoom)in 2021. The focus group discussion was conducted to collect data, which was then analyzed using thematic analysis that explored the experiences, thoughts, and ideas about specific topics. All participants were encouraged to elaborate on ideas to gain more information.

According to Tarihoran et al. (2023) the focus group interview was recorded and transcribed verbatim. Thematic analysis was undertaken following the steps described by Braun and Clarke (2021): of 1) familiarization and data coding; 2) coding; 3) generating initial themes; 4) developing and reviewing themes; 5) refining, defining and naming themes; and 6) writing up. Data analysis included reading and re-reading the transcript and coding using colors and a spread sheet before themes were identified and verified with the research team (Tarihoran, et al.2023. p. 3).

Tarihoran et al. (2023) discovered that impacts of stroke, was by far the largest theme, the impacts were far-reaching and best described using the three sub themes of stroke onset and early experiences, physical and psychosocial effects, and changes to roles and careers.

The participants described having “a stroke as a moment that suddenly changed their entire, previously busy, independent, and productive lives” (Tarihoran, et al. 2023, P .3). These impacts were multiple, affecting every part of the participants’ lives. The participants described physical limitations as one of the most serious impacts of stroke that affected them daily. One participant illustrated the most common physical problems related to motor function, movement, and balance. Tarihoran et al. (2023) saw how their physical limitations also impacted other life skills, like maintaining the house and finances. In addition to the physical impacts, participants in this study described “psychosocial impacts, such as denial because of the inability to do everything others can, loss of confidence, reduced functional independence, and reduced functional independence was one symptom of depression, and the rate of depression in young women after a stroke” (Tarihoran et al. 2023, p. 6). The physical and psycho logical impacts experienced by women after a stroke at a young age are also recognized as seriously impacting their role and career as a woman.

According to Tarihoran et al. (2023) stroke onset and early experiences varied for each of the five women, with the youngest being 21 years and the oldest 63 years. One participant experienced symptoms of "a stroke while driving a car -Chloe", and another one while "talking on the phone -Linda." Yet, another participant developed symptoms when "waking up early in the morning -Liz." (p.3). Most of the participants experienced headaches in the days before the stroke. Stroke causes a serious impact on women because women not only have the burden of typical symptoms but also experience atypical symptoms such as headaches, mental status changes, and dizziness more frequently than men. Reading the participants stroke onset symptoms/experiences in this study gave me the idea to share my own stroke onset experience in chapter four of this study.

The participants felt frustrated hearing their diagnosis and how they were treated because of being younger. The women also described experiencing serious impacts of stroke on their roles and careers, realizing that they could no longer continue like their former post stroke lives because fatigue and lack of energy were common factors or were physically incapable of preforming past job requirements.

Tarihoran et al's. (2023) study described five women's experiences following a stroke from six to 18 years ago. The women were aged between 21 and 63 years old when they had a stroke, which is younger than the 76 years most women experience a stroke, which aligned with an increasing trend of almost fifty percent of new stroke cases occurring among younger people. Despite the small number of participants in this study, "their experiences varied and showed that even if someone had a stroke some time ago, they still needed ongoing support and attention"

(Tarihoran et al, 2023, p.6). The women in this study described their motivation to recover because the women needed to run their family home and return to work; they had a sense of urgency to recover and return to their lives. This motivation can be seen as a positive aspect of post-stroke self-management in terms of maintaining health and preventing complications. The experiences of younger women stroke survivor's provided valuable insights. The challenges younger women face after a stroke are complex and enduring. The long-term consequences of stroke and its many residual complications can have a negative impact on the physical and psychological well-being of the individual and their caregivers, which can then affect the stroke survivor's recovery. Therefore, specific strategies for post stroke rehabilitation for younger women is needed to optimize their health and well-being. The stroke burden experienced by younger women is more complex but less explored than for older populations. Therefore, younger women need to be more aware of early stroke symptoms, and of post stroke opportunities for support. This study helped me to see that younger women stroke survivors like me were motivated to recover and return and needed specific strategies for post stroke rehabilitation to accomplish this.

Stroke Patterns

Lucas, Moulin, Deplanque, Tatu, and Chavot (1998) conducted a study to determine the stroke patterns in 40 consecutive patients with Internal carotid artery dissection (ICAD) which is a frequent cause of ischemic stroke in young patients. Carotid Artery Dissection (CAD) is a serious condition in which a tear forms in one of the two main carotid arteries in the neck, allowing blood to enter the artery wall and separate its layers (dissection). This separation can lead to the formation of a blood clot, narrowing of the artery, and restricted blood flow to the brain, potentially resulting in stroke. Symptoms vary depending on the extent and location of the dissection and may include a sudden, severe headache, neck or facial pain, vision changes, a drooping eyelid. ICAD is an increasingly recognized cause of stroke that accounts for up to 20% of ischemic strokes in young adults. The best therapeutic approach should be determined based on the presumed mechanism of cerebral ischemia, which is insufficient blood flow to the brain. The study was conducted in a retrospective way in 40 consecutive patients admitted to 2 stroke units for a proved ICAD responsible for ischemic stroke.

The study population consisted of 26 women and 14 men, aged 18 to 61 years (mean age, 42.8 years; 95% CI, 39.2 to 46.3). Patients had a total of 45 ICA dissections (26 right, 19 left). Five patients had bilateral ICA dissections; of these 5 patients, 2 had a bilateral ICA dissection with unilateral vertebral artery dissection, and 1 had a dissection of both the ICA and the vertebral artery. 3 with cervical pain, and 3 with headache). Seventeen patients were free of any vascular risk factor. CT scans, MRI scans, and angiographic features were analyzed by observers. Lucas et al. (1998) found “24 patients with abnormal narrowing of the artery (12 right, 12 left), with 20 string signs, inflammation, scarring or narrowing and 21 occlusions (14 right, 7 left) at the acute phase” (p.2646). Eleven patients had dysplasia, and 9 had a pseudoaneurysm on the ICA (6 on the right ICA and 3 on the left). Lucas et al. (1998) collected data by: age (in years), sex, and presence of arterial hypertension and current cigarette smoking, migraine according to International Headache Society criteria, and initial symptomatology (p.2647). Cortical infarcts or tissue death from lack blood flow was a common finding. These 40 patients underwent either 2 CT scans or 1 CT scan (at admission) and 1 MRI scan showing the presence of mural hematoma (n 22) at the acute stage (during the first week); angiography (n 40) was performed at onset during the first week and again 3 months later (n 33). Lucas et al. (1998) found “34 cortical infarcts, 25 large subcortical infarcts, 1 small subcortical infarct, and 5 junctional infarcts" (p.2646).13 patients had multiple infarcts. Patients with multiple infarcts had mainly occlusions (9 patients) rather than stenoses (4 patients). Therefore, cortical infarcts and subcortical infarcts accounted for 92.2% of all infarcts, whereas junctional infarcts accounted for only 7.7%.

A second angiography performed 3 months later in 33 patients showed persistence of the same abnormality in 9, partial reopening in 2, and complete angiographic recovery in 22. The patients had a total of 65 infarcts. All were recent infarcts, except in 1 patient, who had a recent infarct in the left hemisphere due to left occluded carotid artery dissection and an old infarct on the right side, without evidence of old carotid artery dissection or dysplasia. All infarcts were in the territory of the dissected carotid artery except for the previous patient. Lucas et al. (1998) found 34 cortical hemispheric infarcts, 25 subcortical infarcts 15 mm, 1 subcortical infarct 15 mm, and 5 junctional or watershed infarcts, which are ischemic lesions that occur at the junction of two major arteries in the brain. Seventeen patients were free of any vascular risk factor. However, seven patients had a history of preexisting migraine according to International Headache Society criteria, including 3 with an ophthalmic aura migraine. Recent cervical traumas such as carrying a heavy burden, dancing, or painting a ceiling, or obvious, such as chiropractic maneuvers or a car accident) were found in 12 patients. ICAD was associated with headache in 8 patients.

These findings suggested that most infarcts occurred in the carotid artery dissection (CAD) and were probably embolic caused by a blockage of the blood vessel rather than hemodynamic or problems with the actual blood flow in origin showing that a history of preexisting migraine and recent cervical traumas played a role in the pattern of this type of stroke.

Women's Experience of Ischemic Stroke

Beal, Stuifbergen, and Volker, (2012) conducted a narrative study of women's early symptom experience of ischemic stroke. The purpose of this study was to gain understanding of women's early symptom experience of ischemic stroke because little is known about women's experiences in the period between symptom onset and hospital arrival. Early symptom experience encompasses the period from when individuals first noticed the symptoms until their arrival at the ER and is referred to as ‘‘early stroke.’’ Symptom experience is defined as an individual's perception of a symptom, evaluation of the meaning of a symptom, and response to a symptom. In this definition, perception refers to awareness of a change in the body or in functioning, evaluation is a person's opinion about the severity and cause of symptoms, and response may be psychological or behavioral. (p.241).

The sample consisted of 9 women aged 24 to 86 years with an ischemic stroke within 1 year of diagnosis. Letters and fliers explaining the study were distributed at meetings of community stroke groups, and an advertisement was placed in a local newspaper. The occupational and physical therapists at several hospitals distributed recruitment materials to female clients with a diagnosis of ischemic stroke. Inclusion criteria were women 21 years or older with a verified ischemic stroke within 1 year and the ability to speak and understand English. After receiving verification of the diagnosis of ischemic stroke, the participant was contacted to schedule an interview. According to Beal et al. (2012) two research questions were addressed:

(1) How do women experience their bodies from the time of symptom onset until arrival at the ER?

(2) What are women's thoughts, feelings, behaviors, and interpersonal interactions from the time of symptom onset until arrival at the ER? (Beal et al,2012, p.241

The follow-up questions consisted of describing how your body felt, your emotions during the time from when you first noticed symptoms, and your thoughts on what was happening to your body.

A narrative inquiry was used to guide this inquiry because the authors felt this methodology would best display a communicating life event in the form of a story because it is well suited to study time-bounded experiences and episodes in an individual's life. Data was collected using in-depth interviews in which participants were asked to tell the story of their stroke from the moment they noticed the symptoms until they arrived at the hospital. Data collection was achieved through 2 in-depth semi structured interviews with each participant. Interviews were conducted by the principal investigator (C.C.B.) at a place and time of the participants' choosing. The first interview began with a broad introductory statement soliciting the participant's story of stroke from the moment she first noticed symptoms until she arrived at the ER. The second interview took place 2 to 6 weeks after the first interview. The second interview provided the opportunity for participants to share further thoughts and for the researcher to bring forth questions generated by the first interview. The interviews varied in length from 45 to 90 minutes and were audio-recorded and transcribed verbatim. Field notes were written immediately after each interview to capture the interviewer's thoughts about the interview and emerging impressions about the data. Notes were kept throughout the data analysis process to aid in and document analytic decision making. Data were analyzed using sequential methods of narrative analysis. Data were analyzed using sequential methods of narrative analysis. First, individual narrative accounts for each participant were created based on her story of early stroke. Criteria originally developed to evaluate life histories were used when crafting the accounts. The events of early stroke were configured into a temporal sequence that captured the connections between the events and actions that led to the woman's arrival at the ER. The authors found evidence that women arrived at the hospital later than do men.

For Beal et al (2012) the findings reported here are based on the second phase of narrative analysis in which the narrative accounts were compared to identify similar and dissimilar qualities and characteristics of participants' experiences, and then the results of this comparative process were synthesized in written form. The procedure used in the second phase of the analysis used 5 steps:

(1) Reading and rereading the narrative accounts to obtain an overall impression of participants' experiences.

(2) Identifying portions of the accounts related to the 3 components of symptom experience (perception, evaluation, and response).

(3) Identifying the "essential themes and insights'' of these components.

(4) Identifying differences in the accounts and the contextual factors that may have accounted for the differences.

(5) Writing a synthesis of the accounts (Beal et al.2012, p.242-243).

Weakness or numbness, trouble speaking or understanding, trouble seeing, problems walking or dizziness, severe headache are all classic stroke symptoms. For Beal et al (2012) of the 9 women, 6 reported prodromal symptoms, which were defined as symptoms that occur prior to the symptoms noticed within 24 hours of hospital admission. Most prodromal symptoms reported by the participants were classic stroke symptoms stroke, unfortunately, the participants did not realize it. Other causes reported by the participants included heart attack, high blood pressure, diabetes, medication side effects, carpal tunnel, poor circulation, and everyday bodily occurrences such as tiredness, a limb ‘‘falling asleep,’ and muscle strain (p.246). Between the 9 participants they were: overweight, smoked cigarettes, took oral contraceptives, had diabetes and had high blood pressure, which are all triggers for a stroke.

The women in this study experienced a loss of body sense which is an inability to grasp or pick up an object, early stroke was lived out in the world as the inability to accomplish routine activities in usual ways. Stroke meant being unable to rise from a couch, grasp an object, walk in a straight line, and prepare food as usual.

Participants responded to symptoms in a variety of ways, including trying to carry on with usual activities, lying down, seeking help from another person, self-medicating, checking blood sugar and blood pressure, and obtaining medical consultation for prodromal symptoms. Symptom response flowed from a woman’s evaluation of the cause and seriousness of her symptoms, but the interpretation of symptoms as serious did not always lead to prompt help seeking. Instead, it was the meaning of symptoms that appeared influential in symptom response, and meaning was formed within the context of a woman’s life situation. In addition, fear played a role in symptom response by not being in control, and unable to coordinate movements for some women. While other women described bodily changes, including visual disturbances, dizziness, and numbness. These women attributed their symptoms as other side effects of their other conditions they had. Self-image, social roles, and socioeconomic status were seen to influence participants’ decisions and actions in response to symptoms. Some participants’ responses to their symptoms displayed a sense of reluctance not to inconvenience others.

For Beal, et al. (2012) an important finding from this study was that early stroke was experienced at the intersection of a woman’s intention to perform an activity and her execution of that intention in the world. When discussing stroke onset, the participants emphasized the effect of symptoms on their ability to carry out activities rather than “the physicality of changes in sensation” or “function”. For these women, dizziness was not so much a physical sensation as it was difficulty preparing food for the family: stroke was the difficulty preparing food. Women experienced early stroke as “the inability to carry out routine activities in usual ways”, which was accompanied by an awareness that the body was mal functioning and out of control. At times, stroke on set was not congruent with preexisting ideas about stroke onset. “Stroke onset was a process occurring over time characterized by changing perceptions and evaluations of symptoms rather than experienced as a discrete event.” Decisions and actions in response to symptoms were rooted in the meaning of symptoms to the women (Beal, et al., 2012, p.250).

Age Factors for Stroke Survivors

Morris (2011) examines how age influences the psychological adjustment of stroke survivors, particularly regarding service provision and employment in the United Kingdom. The paper is divided into three sections: (a) stroke and psychological adjustment in the young, (b) young stroke survivors' experiences of services, and (c) work after stroke. In this context, a "young" stroke survivor is defined as someone aged 18 to 65 years (Morris, 2011, p.1). The lower boundary aligns with the current distinction between childhood and adulthood, while the upper boundary corresponds to the division between working age and old age health services in many countries. The study is based on extensive literature searches across several databases (ASSIA, AMED, British Nursing Index, Cochrane database of systematic reviews, MEDLINE, PsychInfo, SCOPUS, Zetoc, Google Scholar). Reference lists of relevant articles were examined, and papers citing these articles were also reviewed to supplement the research. Reviews and original articles containing psychologically relevant material were selected for further analysis and potential inclusion.

Morris (2011) reviews the literature on the psychological consequences of stroke in individuals under 65, focusing on services and work. Despite some similarities, young and old survivors experience different challenges and needs. Morris writes, “These are attributable to the effects of stroke on age-normative roles and activities, self-image, and the young person’s stage in the life cycle, especially family and work. Hidden cognitive impairments, a disrupted sense of self, and the incongruity of suffering an “older person’s” disease are salient” (p.4).

Morris (2011) identifies several psychological effects of stroke, supported by evidence. These include reduced quality of life associated with dependence, depression, being single, fatigue, and unemployment. More specifically, stroke survivors may experience loss of home, loss of employment, "psychological paralysis," and difficulties fulfilling roles such as parenting (p.6). Quality of life after stroke is impaired for all age groups compared to healthy adults, with 80%–90% reporting a decline. Healthcare staff reported that about half of survivors experienced psychological disorders, particularly depression or anxiety. Anxiety often centered on work-related issues but also extended to recovery and childcare concerns. Approximately a quarter to a third of survivors exhibited denial, anger, frustration, or hostility. A UK questionnaire survey also revealed problems with employment, finances, social participation, and marital difficulties, including sexual problems. Morris (2011) notes:

These results were echoed in the conclusions of a review of seventy-eight studies of young stroke survivors, and this review also noted that problems were frequently attributed to the stroke. However, the percentage of survivors reporting problems varied considerably across studies and problems, typically from 5% to around 70%. Body image was found to decline following stroke in a mixed gender group under 40 years old. This was most marked in those with left hemisphere strokes and was associated with a reduction in physical and global measures of self-esteem. Frustration was a core theme found in a qualitative study of survivors under 55 years old, for up to two years after a first stroke. (Morris, 2011, p.2).

The frustration stemmed from a sense of psychological paralysis due to pervasive fatigue that affected daily activities and gender roles, particularly those of parent, provider, and housekeeper. It was exacerbated by feeling "outside and invisible," which arose from a lack of information, insufficient consideration of young survivors' needs, limited age-appropriate activities, and their awareness of invisible" cognitive impairments (Morris, 2011, p.2). This study also noted positive outcomes of stroke, including new roles and perspectives that enhanced adjustment. Despite the small sample size limiting generalizability, large-scale follow-up studies and independent research corroborated these findings. Over half of young survivors reported enduring physical and cognitive disabilities and dissatisfaction with post-stroke life. Many faced challenges due to fatigue-induced paralysis and the "invisibility" of their disabilities, which often led colleagues, family, or friends to dismiss or question the legitimacy of the survivor's limitations.

Morris (2011) synthesized four qualitative studies, proposing that young stroke survivors' experiences could be categorized into three overarching domains:

> “Disorientation” due to the sudden effects of stroke, “disrupted sense of self” due to changed self-perception and “loss of control” which may in turn lead to changed priorities, and finally “roles and relationships” which change due to dependency and

> impaired functioning. Many of the effects of stroke are ‘invisible’ but have significant impact on social participation, including the ability to return to work and to enjoy an active social life. Young adults felt the same and yet different following stroke, which had a profound effect on relationships. (Morris, 2011, p.2).

Young adult stroke survivors face the unique psychological challenge of reconciling a condition typically associated with older individuals while being treated in services dominated by older patients. Morris (2011) noted that "younger stroke survivors faced challenges of self-identity, or social identity; or the way that a person views and experiences themselves and their relationships with significant others and social groups" (p.5). Identity plays a central role in psychological adjustment, particularly for brain-injured individuals striving to make sense of their new circumstances. Morris emphasized that "Continuity in self-identity has been proved to impact on the psychological well-being of stroke survivors" (p.6), and "Sense of self-efficacy or competence appeared as an important aspect of identity in a study of young neurological and stroke patients" (p.7). Patients viewed rehabilitation through various lenses, prioritizing independence, self-reliance, determination, and progress recognition. Both healthcare professionals and rehabilitation processes were seen as crucial in shaping self-efficacy, as were interactions with fellow patients.

Morris (2011) attributed the negative experiences of younger stroke survivors in health services partly to a failure in identifying and addressing their specific needs. He suggested that the resulting dissatisfaction and distress may not solely stem from the services themselves, but also from psychological factors related to "a young person's self-concept and identity posed by being treated in services where older people predominate" (p.7).

Regarding employment, Daniel et al. (2009) reported "the mean percentage returning to work to be 44% (range 0 to 100%) in a review that included 70 studies, but studies of return at 6–12 months after stroke found the rate to be slightly over 50" (p. e432). Factors influencing successful return to work include absence of dysphasia (Saeki, 2000), higher functioning on discharge, shorter rehabilitation stays, lack of apraxia, freedom from psychological disorders, preserved cognitive abilities, and low pre-stroke alcohol intake.

Internet-based resources have proven valuable in supporting stroke survivors' return to work. These resources educate both survivors and employers about employment potential and practical aspects of workplace reintegration. The Different Strokes website offers comprehensive guidance through three targeted documents: one for survivors, one for families and friends, and one for employers. Morris (2011) observed that:

> Young stroke survivors have psychological needs which overlap with those of older survivors, but some areas are more prominent in this group. For younger stroke patients supporting social and sexual orientation were crucial factors in regarding their sense of self. These are associated with being at an earlier life stage but also stem from the effects of stroke which makes them feel different and isolated from their young peers and changed from their former selves (p.4).

Morris (2011) found that while young stroke survivors share psychological needs with older survivors, certain areas are more pronounced for the younger group. These needs primarily relate to being at an earlier stage of life and stem from the stroke's effects, which cause young survivors to feel "different" and isolated from their peers, as well as "changed" from their former selves.

Race and Stroke Recovery

Horner et al. (2003) conducted a study on "The effects of race and poverty on the process and outcome of inpatient rehabilitation services among stroke patients." They found that "the greater mortality and residual physical impairments among black stroke patients may be attributable to differential utilization of rehabilitation services" (p. 1027). This study examined racial differences in the initiation time of stroke rehabilitation services and the trajectory of physical function recovery within an equal-access healthcare system.

The study was a secondary analysis of data from an inception cohort of 1,073 stroke patients hospitalized between April 1995 and March 1997, with follow-up for up to one year. Inpatient data came from medical record reviews, while follow-up data was collected through telephone interviews at 1, 6, and 12 months after stroke (p. 1027). The study included consecutive acute ischemic or intracerebral hemorrhagic stroke patients from nine VA medical centers. The main outcome measures were time to initiation of inpatient rehabilitation services and ability to perform activities of daily living. The original cohort was restricted to 738 patients (69% of the 1,073 patients) who were either black or white and referred to inpatient rehabilitation. After adjusting for stroke severity and cognitive impairment, black patients were as likely as white patients to be referred to rehabilitation.

The primary outcome for analyzing physical function recovery was the performance of activities of daily living (ADL) during the first year after stroke onset. ADL performance was measured using the Rankin Scale score at discharge and the Barthel Index after discharge. The Rankin score was standardized to the Barthel percent metric (recoded to a scale from 0 to 100, with 0 being the worst and 100 the best) to allow assessment of relative change from discharge to the last follow-up point.

Horner et al. (2003) suggested that an explanation for their findings may lie in the fact that patients were clinically managed in the VA healthcare system, which, in principle, provides equal access to care for its eligible patient population. This implies that the ability to pay for outpatient rehabilitative care is not a major factor. However, Horner et al. (2003) found that:

> The pace of recovery from stroke is more likely inhibited by other aspects of poverty, such as the absence of supportive social resources (e.g., transportation to outpatient rehabilitation services or access to supplemental in-home rehabilitation services) that may help sustain or enhance the benefits of overtime therapy. This hypothesis derives from work suggesting that early supported discharge with an emphasis on rehabilitation in the home yields improved functional recovery after discharge. If the hypothesis holds, race must be associated with an accentuation of these poverty-related factors that impede stroke recovery so that being black and having low income combine to yield a more negative health outcome than might be associated with low income alone. Poverty-associated factors in the post discharge setting may explain this phenomenon (Horner, 2003. p.1030).

This study was the first to document a significant racial difference in the association between rehabilitative care and later outcomes among stroke patients. Low-income black stroke patients who experienced delays in starting rehabilitation had worse post-stroke physical function recovery, even after adjusting for clinical factors like stroke severity and type. Notably, there was no racial difference in referrals to inpatient rehabilitation or rehabilitation intensity.

Horner et al. (2003) argue that the delay in starting inpatient rehabilitation is unlikely to fully explain the worse functional recovery among low-income black stroke patients after discharge. If delay were the sole factor, all stroke patients—or at least low-income white patients—who experienced delays should have shown worse recovery. However, this was not the case.

Instead, the researchers found that "the trajectory of physical function recovery among the black patients who had higher income, although relatively few, and whites with low income was like that of whites with higher income. Moreover, the average level of function was similar among all race-income groups at discharge. Hence, circumstances in the post hospital environment differentially affect recovery from stroke for low-income black's vis-à-vis low-income whites and patients of higher incomes" (Horner et al, 2003, p1031).

Socioeconomic Status and Stroke Recovery

Twardzik et al. (2019) conducted a study on neighborhood socioeconomic status and trajectories of physical health-related quality of life among stroke survivors. This research was prompted by stroke being the leading cause of serious, long-term disability in the United States, with the number of stroke survivors projected to increase. The study found that physical functioning may be compromised in survivors living in low socioeconomic status environments compared to those in higher socioeconomic status areas. Higher socioeconomic status environments often offer benefits in the built environment, such as sidewalks, accessible transit, or low traffic volume.

According to Twardzik et al. (2019), this study examined the effects of the socioenvironmental context on trajectories of stroke survivors' physical health-related quality of life (PH-QOL) over time by:

> Measures of area-level income, wealth, education, and employment at the census tract level were combined to represent participants' neighborhood socioeconomic status. Linear mixed models were used to predict trajectories of PH-QOL over time, controlling for individual characteristics.PH-QOL theoretically reflects elements of physiological reserve and has been shown to be a powerful predictor of health outcomes, such as mortality and physical function. Acquired functioning limitations because of a stroke, such as physical and cognitive limitations, have repeatedly been found to reduce stroke survivors' PH-QOL (Twardzik et al ,2019, p. 3191).
>
> Despite ongoing cognitive and mobility limitations, some individuals adapt and report a high PH-QOL. This improved quality of life is often achieved through continued engagement in social interactions and participation in valued activities. To minimize PH-QOL decline, stroke survivors can enhance social support, access educational resources, and reduce social isolation.

For this study, Twardzik et al. (2019) drew upon Pearlin's (1989) theory of sociology of stress, which "suggests that attributes of the built and social environment may serve as buffers by moderating the relationship between stressful life events and health outcomes" (p. 241). Twardzik et al. (2019) note that

> Most research into stress starts with an experience; an exigency that people confront and their beliefs of that exigency as threatening or burdensome. Many stressful experiences, it should be recognized, don't spring out of a vacuum but typically can be traced back to surrounding social structures and people's locations within them. Women and younger stroke survivors had better trajectories over time than men and older stroke survivors.

> Higher neighborhood socioeconomic status was significantly associated with better PH-QOL across all time points (β=1.73; 95% CI, 0.17–3.30), after controlling for demographic variables and severity of stroke. The findings prove that neighborhood socioeconomic status, sex, and age are associated with the post stroke recovery process. The results of this study suggest the importance of evaluating the environment surrounding stroke survivors when they return to their home communities. Showing that the most encompassing of these structures are the various systems of stratification that cut across societies, such as those based on social and economic class, race and ethnicity, gender, and age. To the extent that these systems embody the unequal distribution of resources, opportunities, and self-regard, a low status within them may itself be a source of stressful life conditions. (p. 3193 & 3196)

After a stroke, individuals may be vulnerable to indirect negative health consequences due to their surrounding built and social environment. Therefore, it's crucial to examine how structural characteristics in stroke survivors' surroundings influence their trajectories of engagement and participation within their community.

Stroke Rehabilitation and Recovery

After a stroke, many survivors transition to a rehabilitation center to relearn lost skills and assess the affected parts of their brain. Rehabilitation aids in improving movement, speech, strength, and daily living skills, helping survivors regain independence and enhance their quality of life. In my case, I spent five months in an in-patient rehabilitation hospital before returning home and beginning an outpatient stroke recovery program.

Landuo Chen (2016) conducted an interpretive study to investigate the beliefs of first-time stroke survivors and family caregivers regarding engagement in stroke rehabilitation within the community. The study involved "in-depth semi-structured interviews with 22 community-dwelling first-time stroke survivors and caregivers... conducted in 2013" (p.73). After recording, transcribing, and analyzing the interviews using thematic analysis, the researchers identified four major themes:

1. Participants exhibited low health literacy about stroke and expressed a need to learn more about the condition from the hospital.
2. There was a lack of communication and continuity of treatment when stroke survivors transferred between institutions.
3. Patients faced challenges with fragmented post-discharge rehabilitation services.
4. Participants perceived ongoing changes in rehabilitation goals at different stages of recovery.

The study revealed that while all participants were eager to return home, they struggled with the transition from hospital to home care. Furthermore, caregivers felt ill-equipped to provide adequate care to the stroke survivors.

The Experiences of Everyday Activities Post-Stroke: Rehabilitation Importance

Atler's (2016) study "The experiences of everyday activities post-stroke" examined how community-dwelling stroke survivors experience daily activities and identified factors influencing these experiences during occupational therapy sessions. Atler aimed to enhance understanding of the post-stroke lived experience, focusing on describing activity-related experiences in the context of daily life. This study was notable for providing insight into stroke survivors' activity experiences within the framework of actual time use. The research questions were: "What are stroke survivors' lived experiences of pleasure, productivity, and restoration associated with activities in the context of everyday living? What are the factors that influence their experiences associated with daily activities?" (Atler, 2016, p.782).

According to Atler (2016), this mixed-method study involved 23 stroke survivors completing the Daily Experiences of Pleasure, Productivity and Restoration Profile (PPR profile)—a time-use survey—on three separate, self-chosen days within one week. Participants subsequently completed individual, semi-structured interviews. The PPR Profile was designed to capture pleasure (sense of enjoyment), productivity (sense of accomplishment), and restoration (sense of renewal), which have been identified as human need-based experiences associated with everyday activities. "Users stopped 2–3 times in each chosen day to record what they did in their own words, including when, where and with whom they did each activity." Next, users rated their levels of pleasure, productivity, and restoration using a five-point Likert scale ranging from absent to extremely high (Atler, 2016, p.782).

Atler's (2016) descriptive statistics and constant comparative analysis revealed that high levels of pleasure were associated with low-demand leisure activities, high levels of productivity were associated with home management activities, and engaging in hobbies provided the highest combination of pleasure, productivity, and restoration. The study showed that lived experiences of pleasure, productivity, and restoration were influenced by the convergence of internal and external factors. Atler concluded that stroke survivors' "lived experiences of pleasure, productivity and restoration in the context of everyday activities yielded insight into the survivors' recovery and adjustment processes and into their quality of life" (p.781).

Participants' lived experiences of pleasure, productivity, and restoration were all influenced by their strokes. Additionally, the stroke experience influenced how participants determined the varying levels of experience. To maintain confidentiality, identifying information of each participant was removed. Experiences of pleasure described by the participants were related to feelings, with the most common theme connected to feeling good. Words such as "feeling good," "enjoying," "makes me happy," and "fun" were commonly used. Some participants talked about feeling good in connection to being able to engage in activities that might previously have been difficult post-stroke (Atler, 2016, p.784).

Understanding stroke survivors' lived experiences can provide valuable insights to practitioners, family members, and others invested in promoting the recovery process. Lived experiences associated with everyday activities play a central role in post-stroke adjustment and survivors' quality of life. Existing qualitative research demonstrates that stroke survivors use descriptions of their ability to engage in daily activities to explain their post-stroke lived experiences. Other qualitative research focusing on the process of re-engaging in meaningful activities highlighted how stroke survivors' lived experiences associated with everyday activities signaled the need to adjust. As stroke survivors engaged in meaningful activities, their abilities were tested, resulting in either feeling successful or realizing they needed to adapt to their activities. This demonstrates that survivors' lived experiences of everyday activities are fundamental to the adjustment process and underscores the need for research into the factors that influenced these experiences (p.782).

The information gained has important implications for rehabilitation. Understanding stroke survivors' lived experiences provides rehabilitation practitioners valuable information to assist with goal setting and intervention planning. Atler's (2016) study showed:

> A sense of accomplishment may be gained outside of work in home management and high demand leisure activities for survivors with low self-efficacy. Rehabilitation practitioners should consider facilitating stroke survivors’ participation in their hobbies as

> these activities were associated with high level of pleasure, productivity and restoration. Rehabilitation practitioners should consider facilitating stroke survivors' participation in their hobbies as these activities were associated with high level of pleasure, productivity and restoration. Attending to stroke survivors' self-perceptions and self-expectations is critical as these internal factors influence their lived experience. (p.781).

In the section above, I discussed studies that explored factors that can influence the medical diagnosis of a stroke such as gender, sex, age and race. As a medical diagnosis the stroke needs to be identified first, then the type of stroke determined, next the assessment of the damages and finally the treatment strategies on to the rehabilitation. I learned more on stroke as a medical diagnosis in researching for this study than I did at the rehabilitation hospital recovering from a stroke. I also learned there is a correlation between preexisting migraine and an increased risk of a stroke, which is concerning that I am just now learning this and as a lifetime sufferer of migraines. The social diagnosis is dependent on the type of a stroke and the severity of a stroke's disability and how the disability will impact daily living, social interactions and partipation. This next section examines studies and the social consequences of disability.

Disability Concepts and Frameworks

In this section, I highlight and discuss key concepts from the field of disability studies that frame my examination of my journey through and with the effects of my stroke. Rather than a comprehensive examination of the entirety of the field of disability studies, I have chosen elements that have aided my understanding of my own disability and their connection to the construction of my identity, both pre and post stroke.

Enabling Participation for Disabled Young People

Carroll, Witten, Calder-Dawe, Smith, Kearns, Asiasiga, & Mavoa, (2018) created a study that looked beyond barriers in the physical environment to the interplay of personal, social and physical factors that enable or constrain the community participation of disabled young people with the goal of increasing opportunities for effective community participation and full citizenship of disabled young people, and investigated how physical and social environmental factors cohere to support or restrict the everyday mobility and participation of disabled young people. Because participation in community life is vital for health and wellbeing, promoting a sense of belonging, networks of social support and opportunities for physical activity. Disabled young people have lower levels of mobility and participation in recreational activities because of the physical, social, and cultural facets than their peers without disabilities(cited in Caroll et al., 2018, p.1).

According to Caroll et al., (2018) the overarching aim of the study was to foreground the voices of disabled young people to identify and promote pathways for environmental change in order to increase opportunities for their effective community participation and full citizenship by "exploring participation and mobility" using a modified Children's Assessment of Participation Enjoyment questionnaire (CAPE), trip diaries, Geographic Information Systems (GIS), Global Positioning Systems (GPS), and accelerometers. To "access disabled young people's perceptions and experiences of neighborhood spaces, services and amenities, and opportunities and constraints" they face participating in activities in the wider community via qualitative interviews through home-based and in community settings (p.2). While investigating discourses of inclusion-exclusion in specific settings as disabled young people and parents/caregivers talk about community participation and mobility practices to help identify modifiable environmental factors (physical and social) to increase opportunities for mobility and community participation and to create pathways for the lived experience and priorities of disabled young people to inform local planning. This study was located in Auckland, Aotearoa/New Zealand (NZ), participants comprised of 35 young people aged 12–25 years with mobility, vision or hearing impairments. Research methods were applied flexibly– negotiated and adapted to maximize each young person's participation in light of their abilities and preferences. A mixed-methods research design combined objective (global positioning systems, accelerometers, geographical information systems) and self-report measures (travel diaries, and questionnaires) to assess young people's mobility and levels of participation in leisure/educational and employment activities with in-depth interviews exploring their everyday experiences of inclusion/exclusion, and factors enabling or constraining community participation. Settings for data collection were varied, and included homes, schools, other specialist educational facilities, disability-specific recreational settings: wheelchair basketball, and the Auckland Deaf Club, and diverse community/public settings (such as cafes, Auckland Maritime Museum, Auckland Zoo, trains, boats, and work-places. Common variations saw researchers first meet with younger participants at school or other educational facilities, whereas older participants have been more likely to choose a café or work-place to meet. The number and mode of data collection contacts with participants and their families (face-to-face and by telephone) varied across the sample from 3 contacts to 12, with a median of 8 (cited in Caroll et al., 2018,p.3) For the older participants semi-structured interviews followed and built on information gathered during quantitative data collection sessions. Topics covered included participation, sense of belonging, inclusion/ exclusion, friendships, barriers to participation, hopes and fears for the future. Interview settings varied and included the young person's home, educational facilities, cafés, and work-places. All interviews were recorded and transcribed (cited in Caroll et al., 2018,p.7).

Parents/caregivers and disability sector key informant viewpoints on the community participation of disabled young people have also been gathered through in-depth interviews. The study used a mixed-methods ‘toolbox” approach to data collection, combining qualitative, spatial and quantitative methods to gather experiential, mobility, physical activity and participation data (cited in Caroll et al., 2018,p.9). Methods were adapted to accommodate different impairments, ages/life stages, and data collection settings, thereby enabling a high level of participation by young people. Follow-up workshops with young people and parents/caregivers will identify pathways to increase participation and challenge current disabling practices. Methods were adapted to accommodate different impairments, ages/life stages, and data collection settings, thereby enabling a high level of participation by young people. Based on their experiences with this heterogeneous group (different ages, different impairments and levels and patterns of impairment), their toolbox of methods and flexible protocols have extended possibilities for participation in the research and data collection, producing rich triangulated data on the everyday lives of disabled young people. Their research methods and protocol have been adapted to take participants’ access needs into account, as well as variations in their time, energy and availability. Working flexibly with a range of methods and accommodations enabled the research team to work respectfully and effectively alongside participants with diverse lived experience of disability and differing access needs and preferences. The researchers found how potential modifications and accommodations can be plotted out in advance, however, the details are best negotiated in vivo on a case to case basis. Social participation is not a one size fits most. It widely varies to the type of disability and age/life stage of the individual. According to Caroll et al., (2018):

> One participant, “Elena”, explained, disabled young people regularly encounter others who are ‘set in their thinking of what disability looks like’ and who wrongly believe that they know a person’s capabilities and preferences on the basis of a diagnosis or initial meeting. “You can never tell what exactly someone else is dealing with, so you know listening and not judging and actually finding out what they're dealing with, rather than what you assume they're dealing with, is really useful (p.9).

Younger people with disabilities reveal significant challenges in areas like education, employment, social participation, and mental health, with many facing barriers to accessing opportunities and experiencing lower levels of wellbeing compared to their non-disabled peers. This study found that having a “toolbox” of different approaches to aid in social participation for the individual, however, the details are best negotiated in vivo on a case to case basis. I was thrilled to find a study that explored younger people with disabilities experience out in their community using methods adapted to accommodate different disabilities, ages/life stages, that addressed age appropriate activities. I found this study beneficial because I was reminded of my constructed tools that I , too used to aid in my inclusive social activities.

Disability in Higher Education

Federal legislation mandates that most colleges and universities provide equal access and reasonable accommodation for students with disabilities. However, many students do not fully utilize college disability services and accommodations. It is crucial for Office of Disability Services (ODS) personnel to understand the reasons behind this, as they strive to best assist students with disabilities at their institutions. Marshak, Van Wieren, Ferrell, Swiss, and Dugan

(2010) conducted a qualitative study on 16 college students with disabilities at a medium-sized state university.

According to Marshak et al., (2010), this study aimed to "contribute to the ongoing exploration of barriers (institutional and personal) that may prevent college students with disabilities from seeking or making regular use of the disability services and accommodations that are available to them on college campuses" (p. 152). They chose an exploratory, qualitative design to gain a holistic understanding of this phenomenon, rather than testing predictions or hypotheses. The researchers conducted in-depth guided interviews with several current college students with various types of disabilities.

Marshak et al., (2010) conducted this study at a medium-sized state university in the mid-Atlantic region of the United States. They used a convenience sampling design, working with the school's ODS. Recruitment letters were sent to all 327 currently active students who had previously registered with the ODS by providing documentation of a disability. All respondents willing to participate were scheduled for interviews. The final group consisted of 16 college students with disabilities, including a mix of freshmen, sophomores, juniors, seniors, and one graduate student. Approximately 80% of the participants were female, and all were Caucasian. Reported disability types included specific learning disabilities, attention deficit disorder (ADD), seizure disorder, arthritis, cerebral palsy, severe mental health disorders, speech disorders, and visual impairment.

The study's data came from semi-structured (or focused) interviews with the 16 participants. Two researchers developed an interview guide based on their prior professional experiences in special education and vocational rehabilitation. This guide included a list of topics or questions to be covered with each participant, encouraging free responses. Semi-structured interviews are widely used for collecting unstructured self-report data. Two researchers co-interviewed each participant, with interviews lasting one to two hours. All interviews were audio-taped and later transcribed for analysis. The researchers used a subset of the interview guide responses for this study.

For data analysis, the researchers employed an editing analysis style to interpret the qualitative data from the interviews. This approach involved reading transcripts to identify meaningful fragments, which were then used to develop a categorization scheme and matching codes. These codes were used to sort the qualitative data, allowing researchers to identify structures and patterns to better understand the thematic categories (Polit & Hungler, 1999).

To reduce interpreter bias, the researchers used investigator triangulation, involving multiple researchers in the analysis process. Two experienced researchers independently reviewed the transcripts to make initial sense of the data. Marshak et al., (2010) then collaborated to synthesize and agree on overarching categorical themes. They identified five main categorical themes representing the primary barriers participants faced in seeking and using available accommodations in college. A third researcher coded and extracted participant statements related to these categories. Three researchers then independently reviewed the coded transcripts, synthesized and named common sub-themes for each main categorical theme. They agreed on a total of eleven sub-categories, achieving an in-depth, holistic understanding of the participants' responses. Finally, a third researcher conducted Level II coding to identify and extract all sub-category data and statements from the transcripts (Marshak, 2010, p. 155).

Marshak et al., (2010) uncovered five major themes: "(a) identity issues, (b) desires to avoid negative social reactions, (c) insufficient knowledge, (d) perceived quality and usefulness of services, and (e) negative experiences with faculty" (p. 154). Identity issues emerged as the most frequent barriers preventing students from seeking ODS services and accommodations. Within this category, three specific sub-themes surfaced: (a) a desire for self-sufficiency, (b) a desire to shed the stigmatized identity from high school, and (c) a desire not to incorporate disability into their college identity (Marshak, 2010, pp. 156-157).

College Students with Disabilities: Student Characteristics, Academic Environment, and Performance

Fleming, Plotner, and Oertle (2017) conducted a study examining how modifiable factors—peer support, disability services, faculty teaching, campus climate, and self-advocacy—might predict academic performance for college students with disabilities. The researchers sought to understand the relationship between demographics, social-environmental factors, and academic performance.

The study involved 325 students with disabilities from three large state universities. Participants, recruited through university disability services offices, completed an online survey. The sample was predominantly female (67%) and White (79%), with 13% being first-generation students. The average age was 27, and the mean GPA was 3.26.

The survey instrument comprised three main sections: demographics, campus climate, and self-reported GPA. Demographic data included gender, age, race/ethnicity, primary disability, age of onset, and parental education. The researchers used the College Students with Disabilities Campus Climate Survey (CSDCC; Lombardi et al., 2011; Fleming et al., 2017). to assess student perspectives on the postsecondary environment, instruction, and social support. Respondents rated statements on a six-point scale from "never true" to "always true." The study focused on four of the CSDCC's nine scales: peer support, disability services, self-advocacy, and faculty teaching. The CSDCC showed convergent validity with measures of student performance and social inclusion.

Data analysis involved downloading responses from Qualtrics to SPSS version 22. The researchers checked for accuracy, corrected errors, and used median imputations for random missing data (affecting 23 participants and 27 data points). They then employed a two-step hierarchical regression to address the research question.

To understand how various factors influenced academic performance, the researchers used hierarchical linear regression. The first step included non-modifiable demographic factors (gender, race/ethnicity, disability duration, first-generation status). The second step incorporated modifiable factors, including social-environmental influences such as satisfaction with college choice and CSDCC factor scores. The study's findings highlighted the significant role of self-advocacy in student performance, offering clear implications for supporting students with disabilities in higher education.

The Disability Identity

For Shakespeare (1996), questions of disability identity bridge key contemporary debates, including the structure/agency problem and the biology/society dualism. In his chapter "Exploring the Divide," he proposes several ways to examine these issues by charting a new path through these dichotomies. Identity is a complex field, and scholars across various disciplines use the term differently within social sciences and social theories.

Shakespeare (1996) identifies two main approaches to categorizing disabled people as a group: one based on a physical or medical understanding, and the other on a socio-cultural understanding. The first approach conceives disability as the outcome of biological determinism, focusing on physical differences. It defines disabled people as those whose bodies do not work, look different, act differently, or cannot do productive work. This analysis centers on performance and conformity, raising questions of normality by assuming a standard from which disabled people deviate.

The second approach views disability as an outcome of social processes or as a constructed category. The social model concept, arising from the disability rights movement and developed by Disability Studies sociologists, exemplifies this approach. Shakespeare (1996) outlines five ways of identifying disability as a social process:

- The social model, which focuses on the disability as a relationship between people with impairment and a discriminatory society.
- The minoritized group approach, in which disabled people are an oppressed group, focusing on power politics and identity politics, while not necessarily problematizing disability itself. It could be associated with North American disability movement approaches and has a general resonance within self-organized disability politics.
- A Weberian or Foucauldian approach in which disability is a category of social policy.
- Disability as the outcome of definitions inherent in social research methods, for example in the OPCS Disability Surveys that measure the population of those who are disabled.
- Disability as a cultural category. This approach, drawing upon the notion of cultural representation, has precedents in the work of Sontag (1991), illness as a

> metaphor and is also related to Foucault's concept of discursive formation (cited in Shakespeare,1996, pp. 96-97).

Shakespeare suggests that denial and projection play crucial roles in the cultural construction of disability. He offers various ways to understand disability as a social construct without abandoning the social model's emphasis on material, environmental, and policy factors. Shakespeare views disability as a complex social relation, arguing that analyzing discursive practices provides a richer picture of disability. He advocates for a Foucauldian analysis, considering disability as a process of subjection.

Self-identity can be viewed through two lenses: the medical approach and the social approach. Both approaches can relate to the induvial medical stroke diagnosis because the medical approach sees identity as an outcome of physical impairment, focusing on adjustment, mourning, and coming to terms with loss. In contrast, the social approach considers identity as shaped by oppressive social relations, emphasizing societal change, empowerment of disabled people, and promoting a different self-understanding.

A particularly useful metaphor for understanding both approaches is the concept of identity as narrative. This focuses on the stories we tell about ourselves and our lives, constructing accounts that encompass plot, causality, and conflict. This approach offers a nuanced model of identity that resists simplistic interpretations based solely on context or embodiment.

Giddens (1991) summarizes this approach to self-identity: "Self-identity is not a distinctive trait, or even a collection of traits possessed by the individual. It is the self as reflexively understood by the person in terms of her or his biography" (p.53). Identity thus connects the social and personal, involving individuals placing themselves in a collective context. Giddens (1991) further emphasizes that "A person's identity is not to be found in behavior nor—important though this is—in the reaction of others, but in the capacity to keep a particular narrative going" (p.54). Shakespeare (1996) illustrates that:

> The experience of disability as a negative identity arises out of a process of socialization, or in the context of social relations, in which impairment is the sole focus of analysis. As an individualized experience, the structural and cultural context is not challenged, and alternatives to the dominant biomedical paradigm are not available. Difference is either fetishized, as medical tragedy, or ignored, and assimilation is the name of the game. The legitimation accorded them by non-disabled people is predicated on accepting responsibility for their own incapacity and not challenging the dominant order on what counts on the societal concept of normalcy (p.99).

Davis (1997) notes that the "concept of normalcy has not always been in existence, and it is believed to have been born during the industrialization era, and in the advancement of medical technology in the eighteenth and nineteenth centuries" (p.3). During this period, eugenics and statistical measurements were introduced to better understand or control the general population. These notions held significant power to measure, qualify, and hierarchize, affecting the distribution around the norm. The word "normal" implies conformity to a standard or ideal, often compared using a bell curve—a symbol of binary measurements distinguishing the "normal" from the "abnormal."

Alternatively, various forms of denial may occur. A person might claim to be "normal" and try to minimize the importance of impairment in their lives, perhaps through concealment. In Goffman's (1968) terms, they may attempt to "pass as normal." As Goffman highlighted, this involves considerable tensions and difficulties in managing information and interaction. Acceptance involves enduring the challenges of impairment. Finally, another form of denial seeks to "overcome" impairment.

Girlin (1994) posits that "disability as a positive identity is a process, to use Foucauldian language, where subjection opens the possibility of subjectification. From popular culture to government policy, society has evidently assigned you a membership. Identity politics turns necessity to virtue" (p.153). Shakespeare (1996) expands on this, stating, "identity is about belonging, about what you have in common with some other people and what differentiates you from others. At its most basic, it gives you a sense of personal location, the stable core to your individuality" (p.101).

Alongside political activism, cultural forms of self-expression, known as disability arts, develop a sense of shared cultural identity central to these processes. Disability culture offers people a key to identifying as a disabled person, as culture and identity are closely linked concepts. Challenging stereotypes, building solidarity, and recounting new stories all contribute to developing a disability culture. These processes also create new options for disability identity.

The political, cultural, and personal are three interlinked aspects of disability identity. Disability is a powerful identity with the potential to transcend other identities. Shakespeare views the disability identity as a master/mistress status. For instance, it can de-sex people, causing them to be viewed primarily as disabled rather than as men or women, straight or gay. The disability movement, for example, is more open to lesbian and gay disabled people than the lesbian and gay community is to disabled people.

However, Shakespeare (1996) cautions that "it is dangerous to overlook multiple identities and assume that disability is the sole and significant identity" (p.105). Just as white feminists were accused by black women of ignoring the specificities of black women's experiences and even of being racist, disabled people risk ignoring difference. Black disabled people might sometimes have more in common with black people than with disabled people. Sometimes, "the values of the disability movement—for example, autonomy, independence, choices, and rights—may in fact be specifically white, western values" (p.106). An eastern or Islamic approach might emphasize family, solidarity, and mutuality rather than what sometimes appears to be a very individualistic model of liberation.

Class is a particularly powerful determinant of the disability experience. Shakespeare (1996) stresses that "class qualifies and changes the consequences of impairment and reduces exposure to oppressive social relations" (Shakespeare, T, 1996, p.109).

Shakespeare's class and gender are better predictors of his career pattern and income than his impairment. Other people with achondroplasia might experience their disability very differently if, for example, they had the educational opportunities presented to him. Often in identity politics, the issue of class is obscured: both the women's movement and the gay movement have faced criticism for being too middle-class dominated, too concerned with middle-class experiences, and not sufficiently attuned to the problems of poverty and exclusion.

Shakespeare believes people experience disability in many ways, and understanding these differences is best achieved through stories. Stories gather people around them: they must attract audiences, and these "audiences may then start to build a common perception, a common language, a commonality" (Plummer, 1995, p.174). Shakespeare (1996) builds on this, expressing that "the disability identity is about stories, having the space to tell them, and an audience which will listen. It is also about recognizing differences and isolating the significant attributes and experiences that constitute disability. Stories are our way into understanding—to theorizing, and thus to knowing and working to change—our culture and ourselves" (p.111). He believes we may need to develop a nuanced attitude that incorporates ambivalence, for example, towards our bodies. Theory has a part to play in this process; it all starts with having a voice. As Foucault suggests, our task is to speak the truth about ourselves.

In sum, the experience of disability as a negative identity arises from socialization processes or social relations. Hence, disability is socially constructed. The social model approach, the minoritized approach, the Foucauldian approach to social policy, and disability as a cultural product demonstrate how disability is a social process. Shakespeare offers various ways of understanding disability as a social construction while maintaining the social model's emphasis on material, environmental, and policy factors. Disability is a powerful identity with the potential to transcend other identities such as race, gender, class, and ability. Disability Studies has also explored how disability, as a set of meanings, influences and even *structures* social relationships both through and beyond personal experiences of disability. One important example of this development is the concept of ableism, or the compulsory preference for non-disability. Shakespeare's chapter allowed me to better understand the disability identity with its other connections to other social identities and how the sharing of stories is about creating the space to tell them, and an audience which will listen. It is also about recognizing differences and isolating the significant attributes and experiences that constitute disability. Stories are our way into understanding—to theorizing, and thus to knowing and working to change—our culture and ourselves.

Defining Disability

Friedman and Owen (2017) conducted a study on defining disability by examining attitudes towards ableism and disability. They explored the concept of ableism—the compulsory preference for non-disability—using Campbell's (2009) view that ableism, like racism and sexism, describes discrimination towards a social group (in this case, disabled people) and how certain ideals and attributes are valued or devalued"(Friedman and Owen, 2017, p.3). For instance, walking is more socially valued than using a wheelchair (Hehir, 2007).

Disabled people have reported that ableism's negative effects have been socially and psychologically damaging (Bell, 2013; Campbell, 2008; Keller & Galgay, 2010; Ostrove & Crawford, 2006; Overboe, 1999; Palombi, 2012). However, less is known about how ableist attitudes and understandings of disability manifest in groups that don't identify as disabled. Various groups, including rehabilitation counseling students (Pruett & Chan, 2006), teachers (Federici & Meloni, 2008), physician assistant students (Archambault et al., 2008), child protective services employees (Proctor, 2011), and nurses (Aaberg, 2012), hold and act upon abstract definitions and attitudes toward "disability"(Friedman and Owen, 2017, p.3)

As ableism is a social process of discrimination and bias, it's crucial to research factors that may influence ableist ideas and actions. Drawing from critical race studies' approach to understanding whiteness to better comprehend racism (Fine et al., 2007), this study explored how siblings of disabled people—a group that doesn't claim a disabled identity—define and value disability.

One way to explore complex views towards social minority groups is through explicit (conscious) and implicit (unconscious) attitudes. People may conceal their explicit biases or be unaware of their biases, so recent attention has focused on implicit attitudes (Amodio & Mendoza, 2011; Antonak & Livneh, 2000). Friedman and Owen's study found exploring implicit attitudes particularly fruitful, as they may relate to external cues and learned associations, contributing to prejudice and reflecting internalized societal prejudice (Amodio & Mendoza, 2011).

There's a particular need to explore implicit attitudes regarding disability due to specific stereotypes and social norms. For example, it may be taboo to overtly express prejudice towards disabled people, as they're often portrayed as pitiable (Harris & Fiske, 2007; Garthwaite, 2011; Ostrove & Crawford, 2006; Stewart, Harris, & Sapey, 1999). Recent literature has focused on implicit disability attitudes, with studies finding that both non-disabled and disabled participants highly favor non-disabled people and hold high levels of implicit prejudice towards disabled people (e.g., Aaberg, 2012; Archambault et al., 2008; Federici & Meloni, 2008; Pruett & Chan, 2006; Friedman, 2016).

To explore the relationship between understandings of disability and attitudes towards it, Friedman and Owen (2017) recruited participants with unique and varied positionalities to disability. Siblings of disabled people are a heterogeneous group with diverse experiences (p.4). Research findings about the impacts of their experiences have been conflicting (Griffiths & Unger, 1994; Heller & Arnold, 2010). Siblings' attitudes about disability may be uniquely and complexly affected by their experiences with disabled family members. However, little is known about how siblings absorb and reflect meanings of disability.

Understanding siblings' attitudes and perceptions of disability is particularly relevant, as they're more likely to work in disability-related fields (Eget, 2009) and take on increased caregiving roles for their disabled siblings (Burke et al., 2012). Participants were recruited through a national organization supporting siblings of disabled people; having a disabled sibling was an inclusion criterion. While siblings of disabled people experience disability in various ways, their relational and experiential proximity to disability makes them a unique population from which to elicit understandings of disability.

Friedman and Owen's (2017) study comprised 48 siblings. The majority (89.6%, n = 43) were women, with only 10.4% (n = 5) being men. Most participants (85.4%, *n* = 41) identified as non-disabled, while 14.6% (*n* = 7) were disabled (p.6). Participants were asked the open-ended question: "What is your definition of disability?" The researchers also collected data on demographics, political orientation (using a sliding scale), relationships with disabled people, and involvement in disability (Friedman & Owen, 2017, p. 7).

The researchers analyzed participants' disability definitions using thematic analysis, a method well-suited for examining similarities and differences within and across participants' responses (They employed a theory-driven approach, engaging with relevant Before examining the qualitative data, Friedman and Owen (2017) discussed how theoretical frameworks would inform their analysis, focusing on three aspects:

1. Experiences of people that do not identify as disabled like: partners, parents, and siblings with frequent interactions.
2. Longstanding dissemination against disability that affects the understandings of disability.
3. Theorical concepts related to disability, like: social movement, identity, relational, and context embodiment (p.10).

Friedman and Owen (2017) found that siblings of disabled people defined disability through several strong themes, including "disability as preventing or slowing action, atypical function, lack of independence, socially constructed, and as general difference" (p. 12). These themes, when considered together, revealed complex, interrelated understandings of disability. For example, the concept of disability as preventing or slowing action closely aligns with atypical function. This focus on action as an inherent good exemplifies Siebers' (2008) "ideology of ability," which posits that disabled bodies are expected to conform to broad social parameters of functioning. Meanwhile, differences in modes of action are often attributed to individual functional variations. Friedman and Owen (2017) also noted how one participant defined disability, “Someone who is incapable of doing something for themselves or has limited access to do something while another participant identified disability as something that makes you do things differently than the general population” (p.12).

Friedman and Owen (2017) expand on this concept, stating, “Disability, seen through the lens of dependency, formed the basis for relationships that may emerge from necessity, at least identified by these respondents. Disability as a relationship serves as way to think about how disability functions as a social structure” (p.13). Their study also showed how, “parents and siblings of disabled people do not themselves identify as disabled, their knowledges, perspectives, attitudes, and understandings about disability may offer something to Disability Studies” (p.14).

Friedman and Owen's (2017) study demonstrated how viewing disability as a social construct and a general difference might provide insights into reducing ableism's negative effects. A close connection to disability can help challenge superficial stereotypes about disabled people that often influence how individuals perceive and value disability.

The theme of disability as socially constructed invoked the theme of disability as a general difference**.** The latter acknowledges that disability is distinctive in some ways but doesn't necessarily imply negative or deficit-based ideas. Both themes recognize that disability has been constructed and reproduced in certain ways. This connects with other themes, including the emphasis on preventing or slowing action and atypical function**.** The "negative" aspects of disability are often seen as part of larger social forces sustaining certain meanings about disability, focusing on relational spaces as sites where we might learn about how disability and ableism are socially and culturally constructed.

Understanding how such discrimination, termed *ableism,* operates is crucial and may require studying perspectives of people who don't claim a disability identity. Ableism can be expressed in various ways, and examining how a particular group—in this case, siblings of disabled people—understands and values disability may contribute to overall understandings of how ableism works. Thus, Friedman and Owen's study aimed to explore relationships between these siblings' broad societal understandings of disability and their attitudes towards it. To further tease out this relationship, the researchers examined factors that impact how people define disability. Using both social psychological and sociological approaches, the authors contextualized individual attitudes as providing new information about social meanings of disability and set their studies' results against the larger backdrop of debates over disability meanings within Disability Studies. Friedman and Owen's (2017) study revealed "complex understandings of disability, but most often defined disability as preventing or slowing action, as an atypical function, a lack of independence, and as a socially constructed obstacle. Participants' unconscious (implicit) disability attitudes significantly related to their understandings of disability as lacking independence, impairment, and/or in relation to the norm, and their conscious (explicit) disability attitudes" (p. 15). The results revealed implicit prejudice that correlated with participants' explicit prejudice and their definitions of disability.

Friedman and Owen (2017) suggest ways to "disrupt ableism," as Dan Goodley (2014, p. x) proposes. Since ableism is a social process of discrimination and bias, it's crucial to research factors that influence ableist ideas and actions (p. 20). Following critical race studies' approach to understanding whiteness to better comprehend racism (Fine et al., 2007), this study examined how siblings of disabled people—a group that identifies with disability—define and value disability.

Both explicit and implicit attitudes play an integral role in people's "true" attitudes. However, explicit (conscious) attitudes may not reveal all attitudes because individuals might be unaware of their prejudiced views (Amodio & Mendoza, 2011; Antonak & Livneh, 2000). Understanding how disability is defined and perceived requires deeper examination. Unlike racial prejudice, which has been linked to political orientation (Dovidio, 2001; Dovidio & Gaertner, 2004; Dovidio et al., 1992; Sears & Henry, 2005), negative perceptions of disability may transcend political lines (Friedman, 2016). Harmful disability portrayals, representations, and stereotypes are so pervasive that they're often accepted without question and not recognized as negative. Consequently, most people are likely unaware of the problematic nature of their understanding of disability.

Explicit and Implicit Disability Attitudes of Healthcare Providers.

VanPuymbrouck, L., Friedman, C., & Feldner, H. (2020) created a study to examine health care providers' explicit and implicit attitudes, interactions between their attitudes, and correlates of explicit and implicit bias on disability. Because health care providers' attitudes of marginalized groups can be key factors that contribute to health care access and outcome disparities because of their influence on patient encounters as well as clinical decision-making. According to VanPuymbrouck et al., (2020) This study had four research questions:

1. What are health care providers' explicit attitudes toward disability?
2. What are health care providers' implicit attitudes toward disability?
3. What is the relationship between health care providers' explicit and implicit attitudes?
4. What demographic factors are associated with lower explicit and implicit disability attitudes of health care providers(p.102)?

This study analyzed secondary data from 25,006 health care providers about their disability attitudes. In addition to analyzing people's explicit and implicit attitudes (Disability Attitudes Implicit Association Test),and using Son Hing, Chung-Yan, Hamilton, & Zanna's (2008) model of two-dimensional prejudice to compare provider's explicit and implicit attitudes. This study used linear regression models to examine correlates of providers' explicit and implicit attitudes. While on average, provider's explicit attitudes (M 4.41) indicated little prejudice, their implicit attitudes (M 0.54) revealed they moderately preferred non-disabled people—they were aversive ableists. Which correlated the providers' explicit and implicit attitudes also included age, gender, political orientation, and having relationships with disability(VanPuymbrouck et al., 2020 p.101). This study revealed that despite a majority of providers self-reporting not being biased against people with disabilities, implicitly, the overwhelming majority were biased. This study's findings can be used to better understand how provider's disability bias can contribute to inequitable health care access and health outcomes for people with disabilities. As disability bias is extremely prominent (Friedman, 2019), it is likely that providers not only have biased disability attitudes but also demonstrate biased interactions with people with disabilities that are impacted by these attitudes. There is increasing demand for socially and culturally appropriate behavior by providers in clinical encounters, which includes reduction of both explicitly and implicitly biased care by providers in clinical encounters, which includes reduction of both explicitly and implicitly biased care. Understanding both the impact and influence of explicit and implicit biases of providers toward people with disabilities, particularly the interaction between their explicit and implicit attitudes, and if/how demographic factors correlate with their bias is one of the first steps in reducing disability discrimination within clinical encounters(VanPuymbrouck, 2018). Doing so is necessary in order to develop evidence-based interventions targeted at reducing providers' negative attitudes. The study found that more than 25,000 providers revealed the majority of providers self-reported (consciously) not being biased against people with disabilities. Yet, when disability attitudes were explored implicitly, the overwhelming majority of providers were biased against people with disabilities and preferred non-disabled people (VanPuymbrouck et al, 2020 p.106). Despite a growing body of knowledge linking similar health outcomes to providers' clinical decision making, less research has focused on providers' attitudes about disability.

I found this study similar to the previous study, which demonstrates that negative attitudes towards disability is a real concern and a problem that needs to be addressed on how to better serve the disabled population.

Physicians' Perceptions of People with Disability And Their Health Care

Lezzoni, Rao, Ressalam, Bolcic-Jankovic, Agaronnik, Donelan, Lagu, & Campbell, (2021) created a survey of 714 practicing US physicians nationwide to observe how patients with disability are treated. Because the Department of Health and Human Ser vices (HHS) delineating national public health priorities identified people with disability as experiencing healthcare disparities, partially attributing these inequities to common misconceptions about this population. Over the past two decades increasing evidence has documented persistent disparities for people with disability, now including more than sixty one million Americans—numbers that will grow in coming years with the aging population. This survey wanted to observe the attitudes of physicians and specifically whether physicians have implicit or explicit biased views of people with disability. Lezzoni, et al's.(2021) survey found disparities in screening and preventive services, cancer diagnosis and treatment, reproductive and pregnancy care, communication with health care professionals, and satisfaction with care (p.297). Many patient-level factors likely contribute to these disparities, such as patients' complex underlying health conditions, disadvantages in social determinants of health, and patients' preferences for care. Systems-level factors also contribute, including inadequate training of health care professionals, in effective communication accommodations, physical access barriers, and inadequate knowledge among physicians about legal requirements to provide equitable care under the Americans with Disabilities Act (ADA) of 1990. Despite it being more than thirty years since the enactment of this civil rights legislation for people with disability, this population continues to experience inequitable health care on many levels. A Past systematic review of studies investigated racial/ethnic implicit bias among physicians and found that unconscious beliefs significantly affected treatment decisions, patients' outcomes, and other aspects of care. If parallel effects hold for people with disability, physicians' bias toward disability could contribute to health care disparities. Lezzoni, et al., (2021) developed a single survey suitable for physicians serving adult patients and practicing in seven specialties: family medicine, general internal medicine, rheumatology, neurology, ophthalmology, orthopedic surgery, and obstetrics gynecology. The researchers chose the first six specialties because of the likely high prevalence of people with disability in their patient panels and included OB-GYN because many women see gynecologists for routine care, and prior research has found high rates of physical access barriers in OB-GYN practices (p.298).

Lezzoni, et al's. (2021) survey design and testing involved several steps. First, they conducted twenty in-depth, open-ended individual interviews with physicians across the seven specialties who were practicing in Massachusetts to explore their experiences with caring for patients with disability. Second, they conducted three video conference focus groups with twenty-two practicing physicians in the selected specialties from seventeen states nationwide, identified through Sermo, an online social network of physicians (p.298).

Lezzoni, et al.(2021) asked physicians several questions to elucidate the factors underlying their perceptions of people with disability and their care. These questions addressed whether physicians welcomed patients with disability into their practices, perceptions of fairness, the value of caring for patients with disability, confidence in caring for people with disability, and the quality of life of people with disability. This national survey that examined the perceptions of practicing US physicians about caring for people with disability produced troubling findings. Only roughly half of physicians "strongly" agreed that they would welcome patients with disability into their practices. More than four-fifths of physicians reported that people with significant disability have "worse" quality of life than people without disability, and only two-fifths reported feeling "very confident" in their ability to provide the same quality of care (p.301).

Lezzoni, et al's (2021) survey found physicians had confidence in being able to provide the same quality of care was strongly associated with welcoming disabled patients. "All levels of medical education should include more training about disability, including disability cultural competence and etiquette"(p.305). Training that provides greater empathy about patients' daily lives, such as house calls or standardized patients who have disability, might offer important insights. Similar to programs in which trainees take online Implicit Association Tests relating to race and ethnicity, educators could add an Implicit Association Test disability module. Finally, situations in which people with disability confront special vulnerability, such as decision making around crisis standards of care, require heightened attention to ensure equitable care.

I found this study beneficial in that it provided insights on how to correct misunderstandings of people with disabilities by providing more training geared towards empathy.

Ability Privilege

In "Ability Privilege: A Needed Addition to Privilege Studies," Wolbring (2014) introduces the concept of ability privilege, which posits that certain advantages arise from possessing specific abilities, creating disparities between those who have these abilities and those who don't. Wolbring examines various types of privileges through this lens, including public accessibility, community participation, employment, consumption, and competitiveness, as they relate to disabled people and the emerging ability privilege of non-disabled individuals. He categorizes ability privilege as either earned or unearned, allowing for analysis of ability advantages across traditional social groups (e.g., race, class, gender) and between "ability-have" and "ability-not-have" social groups.

Wolbring (2014) defines privilege as "unearned benefits afforded to powerful social groups" (p. 119), linked to various characteristics (e.g., male, race, class, gender). His work contributes to what Peggy McIntosh calls "the growing academic field of Privilege Studies" (McIntosh, 2012) by introducing ability privilege as a dominant societal dynamic. Ability privilege can manifest structurally and governmentally (systemic and conscious) or individually and interpersonally (psychological and unconscious). The acceptability of certain privileges changes over time (Kruks, 2005; Holland, 2008).

One effect of privilege is the denial of marginalized groups' ability to articulate their own experiences (Beck et al., 2001). The disabled people's rights movement developed the concept of ableism to challenge normative body ability expectations and associated privileges (e.g., work, education, societal participation, identity, citizenship). Disablism, within this context, suggests that people with normative body abilities are reluctant to relinquish their ability privileges.Ability privileges extend beyond disabled people's experiences, permeating various societal entities. Examples include the ability to buy a car, climb mountains, or perform academic or manual work (Wolbring, 2014, p. 120). These ability expectations lead to various forms of ability privileges and disablement (Wolbring, 2012a, 2012c). However, many fail to recognize their own privileges, believing certain issues have been resolved.

Employment capacity is a crucial type of ability privilege. Wolbring (2014) argues that media-reported unemployment figures for people with disabilities are misleading. In 2013, workforce participation rates were 20.7% for disabled people and 68.8% for non-disabled people (p. 123). Recalculating unemployment figures yields 18.04%/81.96% for disabled people and 64.06%/35.94% for non-disabled people (United States Department of Labor, 2013), indicating a significant employment privilege.

The debate around earned versus unearned privileges is ongoing. Many view abilities present at birth as earned or natural, leading to questions about laws granting considerations to disabled people (e.g., affirmative action). Some label such measures as reverse discrimination, a topic extensively debated within disability studies and other social groups (Wolbring, 2014, p. 124).

Consumption ability privilege manifests both structurally and psychologically, with some unaware of their consumption privileges. In white, middle-class cultures, certain consumption choices (e.g., buying local, car ownership) carry moral weight, despite relying on systemic unearned privileges. This highlights the interrelation between consumption, environmental, and monetary ability privileges—options often unavailable to disabled people living below the poverty line.

Competitiveness is another often-overlooked ability privilege, valued for its connection to past achievements, current aspirations, and future excellence. Scholars debate whether competitive privilege is earned or unearned.

Wolbring (2014) identifies at least four forms of ability privileges affecting disabled people: systemic and conscious, psychologically unconscious, earned, and unearned. These intersect with dominant race, class, and gender groups. Unearned and unconscious ability privileges are evident in legal terms like "reasonable accommodation" and "undue hardship," suggesting that powerful groups are only willing to relinquish privileges they deem reasonable (Wolbring, 2014, p. 121). Examples include potentially inaccessible "accessible" washrooms or disabled parking spaces that are the same size as regular spaces. This reflects an unconscious ability privilege arising not from lack of awareness but from the belief that access issues have been resolved, creating illusions of structural equality and leading to misjudgments about privileges the non-disabled population already enjoys.

Ability/Disability Binary

In their paper "Desiring and Critiquing Humanity/Ability/Personhood: Disrupting the ability/disability binary," De Schauwer et al., (2021) take up the challenge posed by Goodley and Runswick-Cole's (2016) study to dismantle the ability/disability binary. Their goal is to create a framework where those labeled as 'disabled' can seamlessly join the ranks of those considered human.

Using collective biography as their methodology, the six authors explored their own memories of becoming "abled." They discovered a pattern of desire for, and critique of, humanness similar to what Goodley and Runswick-Cole found in their study participants, who were categorized as intellectually disabled. De Schauwer et al.,(2021) focused on four key points:

- Using collective biography to explore their first memories of becoming "abled" and recognized as normal and human.
- Utilizing childhood photos to unlock memories.
- Challenging the taken-for-granted division between the categories of normal/abnormal and able/disabled.
- Arguing that everyone is different, and all change and become able in unique ways. All are vulnerable and desire to belong in the same world, regardless of the categories imposed upon them.

According to De Schauwer et al., (2021), the six authors engaged in a three-day collective biography workshop in Ghent, Belgium. They shared memories of struggling to meet expectations and demands, extending this line of thought to focus on the concept and practice of 'ability.' Drawing on poststructuralist and new materialist concepts, they generated new vocabularies foreshadowed by Goodley and Runswick-Cole's (2016) study. They explored the desire of those categorized as disabled to live what they perceive as a normal life while simultaneously critiquing traditional understandings of personhood. The authors "troubled, reshaped and re-fashioned traditional conceptions of the human (to 'dis' typical understandings of personhood) while simultaneously asserting disabled people's humanity" (p. 2). In tackling this dual task of desire and deconstructive critique, and using the terms personhood, normality, and humanity interchangeably, they aimed "to find new vocabularies in order to honor the humanness inherent in dis/ability alongside its disruptive potential" (Goodley and Runswick-Cole, 2016, p. 1).

Their goal was to expand the concept of "human" to include forms of human life currently separated out and treated as lying outside the norm or even as less than human. They achieved this by employing the concept of dis/ability, which Goodley and Runswick-Cole (2016) developed out of the political necessity of retaining the category of disability. De Schauwer et al. (2021) approached difference not as categorical, but as differentiation or becoming. By adopting these poststructuralist concepts, the authors could focus on what they might become, rather than on restrictive categorization practices and normative individualizing concepts of personhood.

De Schauwer et al., (2021) adhered to Goodley and Runswick-Cole's definition of humanity, which extends beyond conventional understanding. For instance, they define being human as "(normative) citizenship (associated with choice, a sense of autonomy, being part of a loving family, the chance to labor, love and consume…" (Goodley and Runswick-Cole 2016, p.

3). The "dis" in dis/ability prompts a re-evaluation of "how we choose to act, love, work and shop" (Goodley and Runswick-Cole, 2016, p. 4).

For this project, the authors employed collective biography methodology to explore what it means to be human as an emergent subject in relation to others and to reconsider the concept of "ability" (p. 4). The team comprised six differently abled individuals, all of whom had experienced being placed in subordinated categories, such as girls, women, non-native English speakers, and colonial subjects.

De Schauwer et al. (2021) describe how the workshop began with four childhood photos brought by the authors, each evoking memories associated with ability. One photo showed a young girl learning to ride a bicycle, remembering her fear of falling and disappointing adults. Another depicted a young girl on a school ski trip, anxious about disappointing her teacher despite her parents' claims of her skiing talent. The third photo featured a young girl in a forest, ostensibly enjoying nature but terrified. The fourth showed two sisters on a playground appearing happy, though one girl recalled feeling uneasy after helping her sister cheat on an exam. The authors wrote down their stories, read them aloud, and then rewrote them, building conversations around each picture and story. Writing their memories in conjunction with photos helped immerse them in the moment of each memory, allowing them to relive it and discover how it felt in their bodies, in relation to the materiality of those spaces. The photos also helped avoid moral judgment, a key principle of collective biography work. They experimented with perspective-switching, rewriting their stories from the viewpoint of another person in the photo (De Schauwer et al., 2021, p. 6).

While their memories of being recognized as able were initially singular, they became collective through collaborative work, using their stories to tap into the assembled forces at work on human lives. Paradoxically, the more they worked to make these forces visible, the more vivid the material specificities of each memory became. The intra-active process of the workshop and subsequent collaborative writing meant the stories evolved in response to being heard—interacting with others' stories, affecting and being affected by each other's memories. The memories were collective insofar as they were evoked by the shared topic the participants chose to explore together. The memory stories were collectively situated in the workshop's space-time: the shared photos, the physical setting, and the affective bodies working and writing together. Through this process of telling, listening, and rewriting, the memories remained intensely personal while becoming collective within the collective biography assemblage. It was through narrating their stories, listening to each other, and witnessing and acknowledging one another what it means to be human in these ways emerged. The workshop participants, like Goodley and Runswick-Cole's "dis/abled" participants, were all caught up in the human condition.

After the workshop, De Schauwer et al. (2021) delved deeper into the question: how does the material they produced contribute to their thinking about ability? They relistened to all the conversations which they had audio-recorded, to revisit the discursive and material forces in their stories on ability and what they had uncovered. They selected stories for their paper that would allow them to gather emergent insights and expand upon them. Their inquiry shifted from 'what is ability' to 'what is intra-acting to generate what will be recognized as ability'. In revisiting ability, they opened an intra-active space of entanglement where humans, discourses, values, and spatial-material elements affect each other. They explored the moment-by-moment production of ability and how it is made to matter (De Schauwer et al., 2021, p. 292).

De Schauwer et al. (2021) found that they were all attempting to pass as rightful members of the able(normal) category, covering up and pretending to be able out of fear of being considered abnormal, stupid, or incapable. They became adept at fulfilling society's unspoken expectations and negotiating them. They didn't simply strive to meet existing expectations; they learned to be dissatisfied with merely being 'good'. They aspired to become the 'best' and to excel at being normal (p. 293). They learned to manage and organize their lives to belong and fit in. Passing depends on the ability to pretend and cover up incompetence. We learn to hide uncertainty, interdependency, and fear. Goffman (1963) describes passing as "the management of undisclosed discrediting information about self" (p. 42).

De Schauwer et al. (2021) discovered that passing as abled and normal relied on the illusion of having achieved, through one's own efforts and in one's own body, the required standards of performance for being recognized as a normal/normative human being. It was through passing, and the moments of being and becoming Ability Privilege: A Needed Addition to Privilege Studies, that one was enabled to pass as abled. To be abled meant to be seen as an individual in control, with choices, and as belonging to the dominant group of the abled.

Conclusion

In summary, the thematic literature on post-stroke experience highlights the embodiment of self and self-roles—particularly in relation to gender—are crucial elements in the recovery process. These aspects are important to incorporate into this study, as in my own post-stroke recovery, I strived to regain my power, independence, freedom, and sense of self. The stroke rehabilitation experience reminded me of what my caregivers (mother and father) and I all faced: a lack of information on stroke and unpreparedness upon returning home. Age emerged as a significant factor for stroke survivors, with young and older survivors having different experiences and diverse needs. These differences are attributed to the stroke's effect on age-normative roles, activities, self-image, and the individual's life stage.

The literature also revealed hidden cognitive impairments, a disrupted sense of self, and the incongruity of suffering an "older person's" disease as salient psychological effects of stroke. Evidence for these effects included reduced quality of life, associated with dependence, depression, being single, fatigue, and unemployment. More specifically, stroke survivors often faced loss of home, loss of employment, "psychological paralysis," and difficulties fulfilling roles such as parenting and maintaining a social life.

I have presented past studies to inform, guide, reference, and provide contextual information for my autoethnographic study on my post-stroke experience. This literature review is designed around relevant themes such as post-stroke experience and disability. These studies provided the information I needed to fully understand both the stroke medical diagnosis as well as the social and disability diagnosis. Thus, I have utilized the concepts and aspects of this literature review to organize my inquiry within the broader contexts of curriculum making, educational experience, and aspects of my own learning, epistemology, and environment to contextualize my post-stroke embodiment experiences.

Chapter Three: Methods

This chapter explores the methodological framework and approach of autoethnography, with a particular focus on its application in disability studies. The discussion begins by establishing the epistemological foundation, rooted in social constructivism, which underpins the research. This paradigm views knowledge and reality as products of social interaction, providing a lens through which to examine societal attitudes towards disability.

The chapter then delves into my positionality, emphasizing the importance of transparency and reflexivity in autoethnographic research. It outlines the key principles and methods of autoethnography, highlighting its unique characteristics as a qualitative, self-focused, and context-conscious research method.

Following this, the text explores autoethnography as a constructionist project, drawing on the work of Ellingson and Ellis (2008) to examine how this method challenges traditional dichotomies in research and enables critical reflection on societal norms. The chapter continues by discussing specific autoethnographic resources and studies related to disability, which serve as references for my own research. Finally, it discusses how the process of currere informed specific methodological choices in terms of data collection and analysis.

This chapter also provides a comprehensive overview of the methodological approach and theoretical framework that guided this autoethnographic study. The social constructivist paradigm has been chosen as the epistemological foundation, recognizing that knowledge and reality are constructed through social interactions. This framework allowed for a critical examination of how disability is socially constructed and how it shapes individual experiences and identities. Here, I view knowledge as constructed through interpretation and social interaction. I examine people's knowledge of disability and how it is understood and interpreted, and how this may impact how people perceive an issue, affecting their opinions and potential actions related to it.

This chapter also outlines key principles and methods of autoethnography, emphasizing its qualitative, self-focused, and context-conscious nature. The methodological tenets, including the use of personal experience as primary data, deep self-reflection, and linking personal experiences to broader cultural contexts are outlined as elements that were crucial in exploring my personal journey of losing a non-disabled privilege and gaining insights from a new disability identity.

In addition, this chapter provides a rationale for choosing autoethnography as my research approach. Autoethnography allowed my personal experiences to become valid data by permitting my experiences to play a valid role in the study, because this genre includes the researcher as a participant. These elements contributed richness to the data allowing me, as the researcher, to provide unique glimpses both of my own story and of the study.

Epistemology and Framing

I found it best to use the social constructivist paradigm, an epistemology in which knowledge is constructed through social interaction and reality is viewed as a social construct. By working within this sociological, economic, and cultural framework, I can examine the language and attitudes that people, culture, and society have imposed on the concept of disability, limiting its agency and inclusiveness. Chang (2016) stresses that constructivism suggests that human interaction shapes reality, and that knowledge is a human product socially and culturally constructed. Individuals create meaning through their interactions with each other and their environment. Social constructivism highlights the importance of culture and context in the process of knowledge construction and accumulation (Harris, K.R., & Graham, S., 1994). As an interpretive paradigm, this will enable me to examine how attitudes on identities are socially formed, more specifically how I learned to view my new disability identity through socially constructed knowledge.

Through my own experiences, I have encountered different ways of physically, cognitively, emotionally, and socially experiencing and making meaning of the world. The social construction of disability offers a new lens for understanding ability and disability as a social construction that frames how society understands and interacts with individuals who behave in ways that are different from the norm. Incorporating the social constructionist approach, I will focus on understanding how social realities are actively created through language, interactions, and cultural contexts by emphasizing the importance of perspectives, power dynamics, and the role of discourse in shaping knowledge. It is important to critically reflect on taken-for-granted aspects of society, groups, and relationships. This becomes a space in which an individual's passion can bridge individual and collective experience to enable richness of representation and complexity of understanding.

Researcher Positionality

As a researcher, my goal is to provide readers with a transparent and systematic approach to the research methodology. I base my work on the premise that knowledge is socially situated and emerges through the interaction of subject and object. This study focuses on my personal experience of losing non-disabled privilege and gaining insights from my new disability identity. I wanted a research design that would best display and structure the use of personal experience as primary data, deep self-reflection, and linking personal experiences to broader cultural contexts; and how data will be collected, analyzed, and interpreted. I acknowledge that I cannot fully understand the experiences of others with disabilities. As an autoethnographer, I draw from my own experiences and cultural interpretations that reflect my understanding of what it means to be disabled and how these experiences have shaped my identity.

To maintain transparency, I used self-reflexivity to distinguish between my subjective experiences and objective facts by incorporating external sources, including previous studies and literature. To accomplish this, I regularly recorded my thoughts and feelings. physical sensations related to my experience in my reflective journal. I constantly reflected on my behavior and evaluated how its components contribute to ensure that my bias does not affect my interpretations. Now that I am disabled, the way I view the world has dramatically changed because I now must seek out ADA accommodations such as handicap bathrooms, handrails, curb cutouts, and ramps before I go anywhere new by either checking online or going early. An non-disabled privilege I took for granted and gave no thought to because it did not affect me. Ironically, now that is all I see. This awareness informed me of the choices I made in terms of research design, data collection, and data analysis. Now as a researcher, I make notes in my journal on where accommodations were or were not by regularly writing down thoughts and feelings about my interactions with others, paying close attention to my initial responses and reactions I had to situations or to individuals. To accomplish this, I engaged with the existing theoretical frameworks used in the studies I examined. I reflected on my experiences by connecting my personal stories to the concepts and constructs within my theoretical framework. I identified how my experiences aligned with or challenged the theoretical framework to interpret and connect to broader social and cultural issues, which entailed comparing my experiences to established research in the field to identify similarities and differences to provide context. In other words, I recognize that my awareness as a person with a disability greatly informed my researcher role, and I looked for ways to formalize this awareness.

Recognizing that my disability was a huge element of my self-identity, I relied on past studies to gain knowledge about stroke and disability to contextualize my disability beyond my positionality. More specifically, I compared past studies on strokes that addressed gender and the implications of sex as the biological characteristics that have led younger women to experience strokes, and the types of strokes that are common in younger women like me. Age emerged as a significant factor for stroke survivors, with young and older survivors having different experiences and diverse needs. These differences are attributed to the stroke's effect on age-normative roles, activities, self-image, and the individual's life stage. I found similarities to the women in Beal et al.'s (2012) study discussing their stroke symptom experience, as I, too, experienced blurred vision and a severe headache as a stroke onset symptom. In Tarihoran et al.'s (2023) study, they displayed a loss of confidence, reduced functional independence, and reduced functional independence was one symptom of depression, and the rate of depression in young women after a stroke (p.6).This study described the women’s onset stroke symptoms, which gave me the idea to describe and add the elements of my stroke onset symptoms in my research. I felt that this additional element would contribute a richness to my stroke journey.

Overall, I found few similarities in these studies to compare to my own post-stroke experiences; because strokes affect different parts of the brain allotting different outcomes, which would be considered a limitation to my autoethnographic study.

I recognize that I can never objectify my life to such an extent that it becomes completely foreign to my self-as-researcher. However, I tried to remain reflective in my use of self-interview, journaling, and participant observation to collect data. I paid attention to key events, turning points, and significant moments that revealed insights about my lived experience. I used these key events, turning points, and significant moments that revealed insights for my snapshot memories or vignettes to display my understandings. I reviewed my journal, then I recounted my experiences in my currere process. After reading my journals, I wrote field notes based on those journals, in which I recorded as many details about specific events as possible. After recording field notes, I read, reviewed, and reflected on the field notes and subsequently used their content to create a series of my snapshots. Each snapshot captured a significant moment in my post-stroke experience. My story is a collection of those snapshots, followed by a reflection section in which I try to learn from my experiences and find meaning in them. After writing my reflections, I read the snapshots and reflections again to incorporate analysis. In doing this process, I was able to create some distance between these snapshots and my researcher role, always recognizing that the line between both was very thin.

Autoethnography Description (Key Principles and Methods)

Autoethnography powerfully expresses the lived experience of specific cultural phenomena. Chang (2008) suggests examining material attributes at play, such as border crossings—entering unfamiliar places where one struggles to relate or understand their new surroundings. She recommends that auto-ethnographers begin with a life-changing experience, then journal about it using the five senses: smell, sight, touch, taste, and sound. Chang (2008) also outlines six steps:

1. Write and contextualize broadly, exploring behaviors and emotions.
2. Look for patterns and themes.
3. Connect the present with the past.
4. Analyze relationships between self and others.
5. Compare with social science constructions.

6. Frame with theories and present findings as a narrative, poem, drawing, painting, or other creative form (p. 52).

For my autoethnographic study, I added an extra step of conducting a self-interview that consisted of such questions: How has your life changed since your stroke? What have you learned? Are there aspects in your pre-stroke life that you took for granted? What do you want people to learn from your study?

Snapshots would convey Creswell's (2007) recommendation of using autoethnography when researchers seek to understand "cultural perspectives" (p. 123) through their own personal experiences. This research method is distinctive from others in three ways: it is qualitative, self-focused, and context conscious. First, autoethnography is a qualitative research method (Chang, 2007; Denzin, 2006; Ellis, 2004; Ellis & Bochner, 2000). Ngunjiri, Hernandez, and Chang (2010) illustrate, "as a research method, autoethnography takes a systematic approach to data collection, analysis, and interpretation about self and social phenomena involving self" (p. 2). Second, autoethnography is self-focused. Third, autoethnography is context conscious. Rooted in ethnography (the study of culture), autoethnography intends to connect self with others, self with the social, and self with the context (Reed-Danahay, 1997; Wolcott, 2004). Autoethnography relies on ethnographic methods and autobiographical data to interpret culture and connect the self with others (Chang, 2008). In fact, "Good autoethnography… is a provocative weave of story and theory" (Spry, 2001, p. 713).

The methodological tenets of autoethnography include using personal experience as the primary data source, deep self-reflection (reflexivity), linking personal experiences to broader cultural contexts, employing evocative narrative presentation, and acknowledging the researcher's subjective position within the study; essentially, exploring one's own lived experiences to analyze and critique cultural norms and practices through a deeply personal lens. Autoethnography involves several core components that distinguish it as a qualitative methodology. These key elements include a focus on personal experience, the researcher as subject, reflexivity, evocative narrative presentation, and linking the personal to broader cultural contexts (Jones, Adams & Ellis, 2013).

Visibility of self refers to authors' clear presence in their work, which consists of personal, lived experiences recreated for readers, where autoethnographers expose their lives, their experiences, and their feelings. Strong reflexivity "entails self-conscious introspection guided by a desire to better understand both self and others" (Anderson & Glass-Coffin, 2013, p. 73). Through engagement, researchers examine their lives as they would examine others; autoethnography acts as a mirror or reflection of those lives to improve their understanding of themselves and others. The author intentionally tries to engage readers in a reciprocal relationship with the text.

Personal engagement is used as a "medium through which deeper understanding is achieved and communicated" (Anderson & Glass-Coffin, 2013, p. 74). Because autoethnographers work from inside knowledge rather than just textbook knowledge or observation, they can make a connection with readers and use collective experiences and intersections to understand self and others. This active engagement creates reciprocity with readers, which compels a response from them (Holman Jones, 2005). The key is to create a detailed account by showing the reader. The early stages of autoethnographic writing force authors to relive painful experiences. Through vulnerability, reflection and analysis may reveal unpleasant characteristics, and sharing personal experiences with readers may require a public display of flaws, weaknesses, descriptive struggles, and sometimes unflattering scenes.

Richardson (2001) suggested that autoethnographers remain open and vulnerable in field notes but reflect in detail in the write-up.

Strong reflexivity "entails self-conscious introspection guided by a desire to better understand both self and others" (Anderson & Glass-Coffin, 2013, p. 73). Researchers examine their lives as they would examine others, autoethnography acts as a mirror or reflection of those lives to improve their understanding of themselves and others. As autoethnographers, we examine our personal lived experiences in reference to the experiences of others, purposefully commenting on culture and cultural practices to "illuminate more general cultural phenomena" (Jones, Adams, & Ellis, 2013, p. 23). According to Richardson (2000a), strong reflexivity is essential in autoethnography as autoethnographers seek to show "two selves"the "before self" and the "after self" that emerges after a transformational experience (Bochner, 2000).

Autoethnographers must be visible in their work, reflect on personal experiences, engage with readers, and evoke emotional responses in readers. Autoethnographers also need to analyze the story and connect it to relevant literature; that is, the text should demonstrate "knowledge of past research on a topic" (Jones, Adams, & Ellis, 2013, p. 23) and make a substantive contribution to the field of social science research (Bochner, 2000; Richardson, 2000a; Richardson, 2000b). This contribution should offer something new or a new angle to existing research (Ellis, 2009).

I chose autoethnography because it enabled me to tell the story of my life-changing experiences of my post stroke life and would best incorporate my views, thoughts, and story. More specially for its ability to examine how contextual factors—culture, society, and relationships—shape or fail to shape experiences. This method allows for deep introspection, accessing thoughts, feelings, and bodily sensations connected to experiences. It blends vivid, emotive memories with broader social and cultural aspects, transforming experience into a rich, contextual story. Using autoethnography permitted my experiences to play a valid role in the study, because the genre includes the researcher as a participant. Autoethnography allowed my personal experiences to become valid data. These elements contributed richness to the data, both because they are innovative and because they allowed me, as the researcher, to provide unique glimpses both of my own story and of the study. Because I am also a stroke survivor, using autoethnography enabled me to explore my subjective and cultural experiences. My reality, as researcher-participant, is seen through a unique window to the world (Mykhalovskiy, 1997), one that could have been experienced only when participating actively in the study by self-interviews and participant observation.

Autoethnographic Resources

To better help my understanding of how to conduct an autoethnographic study, I examined how autoethnography can interact with a constructionist framework, as well as three autoethnographic studies on disability. These served as references for their use of process as method, language, and similar experiences with disability to compare to my own experience and gain insights on the methodological choices of my own study.

Autoethnography as Constructionist Project

In a chapter titled "Autoethnography as constructionist project," Ellingson and Ellis (2008) explored autoethnography as a social constructionist project. They wanted to explore how autoethnography makes connections between dichotomous aspects of social constructionism. Autoethnography operates as a bridge, connecting autobiography and ethnography to study the intersection of self and others, self, and culture. Ellingson and Ellis (2008) view autoethnography as a social constructionist approach that enables critical reflection on taken-for-granted aspects of society, groups, relationships, and the self. Autoethnography becomes a space in which an individual's passion can bridge individual and collective experience to enable richness of representation and complexity of understanding. "Social constructionism is an approach particularly adept at challenging fundamental dichotomies, not only those in society in general but also those that structure traditional approaches to research, such as: self–other, subject–object, process–product, researcher–researched and personal–political" (p. 448). Ellingson and Ellis (2008) write:

> The practice of autoethnography presumes that reality is socially constructed, and that meaning is constructed through symbolic (language) interaction. Presuming that reality is socially constructed enables autoethnographers to counter accepted claims about "the way things are" or "the way things always have been." Autoethnography is a broad and wonderfully ambiguous category that encompasses a wide array of practices. As authors, we remain ever cognizant of how we participate in the social construction of the field of autoethnography by participating in this discourse that is both autoethnographic and about auto ethnography (p.450).

Ellingson and Ellis (2008) express that socially constructed categories consist of social institutions, laws, regulations, and media. It is the ideas that are created, maintained, and changed over time, which control the conditions, convert observations to numerals, and separate truth from practice—are rhetorically constructed to privilege the powerful elite and marginalize other voices that is a privileged status in the process of knowledge production. Autoethnography attempts to "disrupt and breach taken-for-granted norms of scientific discourse by emphasizing lived experience, intimate details, subjectivity, and personal perspectives" (p. 450). Thus, autoethnography as a method participates in the ongoing social construction of research norms and practices while it seeks to influence the social construction of specific phenomena.

As for the self-other in social constructionist theory, the self exists only in relation to others. The self is not a discrete, individual, or a fixed entity. We understand the self "not as an individual's personal and private cognitive structure but as discourse about the self—the performance of languages available in the public sphere . . . the self as narrative rendered intelligible within ongoing relationships" (Gergen, 1994, p. 185). Autoethnography points to the self as embedded in cultural meanings. Doing autoethnography affects the social construction of the author's self. People make sense of their experiences through the stories they develop about them. For Ellingson and Ellis (2008), these stories are continually altered, never static; we can retell them in ways that make them fit better the "I" who tells them. Doing autoethnography affects individuals who do the work of "re-storying" their lives; the autoethnographic story becomes part of life, an element of the ongoing construction of self. At times, the story stands in for the experience itself and becomes what one remembers as the experience (p. 455).

As for the subject-object from a social constructionist perspective, objectivity is not fundamental or inherent in science but "is primarily a linguistic achievement that draws on the machine metaphor of human functioning" (Gergen, 1994, p. 165). Ellingson and Ellis (2008) believe "claiming objectivity does not make it so but rather signifies the power and authority of a person or group to assert their perspective over that of other persons or groups" (p. 452). Because power and knowledge intricately intertwine, the authority to judge and label some knowledge as objective—and thus valuable—ensures that the powerful remain so, as knowledge disputing the status quo power relations is always already delegitimated. Autoethnography interferes with the dichotomy by "drawing blurry lines between detached, external knowledge and personal, internal knowledge" (p. 452). Much of the rhetorical force of this dichotomy lies in the invocation of objective accounts as rational and of subjective ones as emotional. In actual practice, however, reading emotions of self and other often forms a necessary precursor for rational action.

As for process-product, autoethnography encompasses both process—what one does—and product—what one gets after it is done. Autoethnography reflexively celebrates and often explicitly integrates processes into the product. Revealing and interrogating the processes of research is critical to autoethnography and counters the historical imperative to obscure the details of the construction of research findings using sanitizing strategies such as passive voice while participating in interactive reflection with others. Autoethnographers engage in embodied action, not just report on distant processes. Ellingson and Ellis (2008) believe that this often takes the form of revealing the researcher's complex role in a study of a specific context and of acknowledging the messiness and mistakes that inevitably imbue the process of conducting such research (p. 453).

As for researcher-researched, the researcher-researched dichotomy is undone, or at least unraveled, by autoethnographies in which the author becomes a participant and the author's experiences, emotions, and meanings become data for exploration. To a greater or lesser extent, researchers incorporate their personal experiences and standpoints in their research by starting with a story about themselves, explaining their personal connection to the project, or by using personal knowledge to help them in the research process. Ellingson and Ellis (2008) illustrate that qualitative methodologists refer to the process of researching the self as introspection (Ellis, 1991b). Introspection involves the researcher in generating diaries, journals, free writing, field notes, and narratives of his or her lived experiences, thoughts, and feelings, and then using these as data. "Resurrecting introspection (conscious awareness of awareness or self-examination) as a systematical sociological technique will allow social constructionists to examine emotion as a product of the individual processing of meaning as well as socially shared cognitions" (p. 451). As for the personal-political, what should be private and what should be public, what is an individual issue and what is a matter for the collective to address, often figures prominently in autoethnography. Autoethnographers bring painful, intimate topics to share with others. Many times, autoethnography sheds light on uncomfortable issues that others wish would remain hidden. For example, Ellingson and Ellis (2008) illustrate that autoethnographies can feature stories of resistance to stigmatizing labels. As Kenneth Gergen (2006) suggests, "When one commits to the dominant logics, values, and sanctioned patterns of action within a group, it is often at the expense of hushed but valued impulses to the contrary" (p. 122). Giving voice to those hushed impulses becomes a political act because language is indeterminate and imbued with power relations. Autoethnography troubles the socially constructed categories by showing how they play out in the world and how we incorporate them into our identities—or do not. Hacking calls this an "interactive" kind of classification, as those who are classified modify their behaviors and beliefs because they are affected by the classification label (Ellingson & Ellis, 2008, p. 455).

The concluding pages of this chapter feature the two authors having a dialogue discussing the usefulness of dichotomies. Ellingson and Ellis (2008) posit autoethnography troubles taken-for-granted dichotomies, such as the socially constructed categories by showing how they play out in the world and how we incorporate them into our identities—or do not. While autoethnography can also reinscribe them. Autoethnography interferes with the dichotomy by "drawing blurry lines between detached, external knowledge and personal, internal knowledge" (p. 452). Dichotomous thinking encourages people to think in terms of dichotomies because it constructs positions from both sides. Allowing you to pick a side, take a position, and make a case to defend the work.

According to Ellingson and Ellis (2008), autoethnographies offer many qualities for qualitative research through writing, story, and method that connects the self to the personal to the cultural, social, that enables critical reflection on taken-for-granted aspects of society. Autoethnography as a social constructionist approach enables critical reflection on taken-for-granted aspects of society, groups, relationships, and becomes a space in which an individual's passion can bridge individual and collective experience to enable richness of representation, complexity of understanding.

An Autoethnography on Raising a Disabled Child

In a notable autoethnography, a new mother was advised to institutionalize her autistic child, being told she would never truly experience motherhood (Zibricky, 2014). Rejecting this counsel, she instead embarked on a journey of research and learning about autism. Fifteen years later, C. Dawn Zibricky (2014) chronicled her experiences raising a disabled child. Her study explored seven significant experiences, framing them within the theoretical contexts of motherhood studies and Disability Studies. For each experience, Zibricky critically reflected and systematically analyzed how her firsthand encounters intersected with these fields. Her inquiry revealed four recurring themes: judgment, predictability, disappointment, and fear. Zibricky observed, "Since becoming a mother of a disabled child, I have encountered the beliefs created by the authoritative institutions of society including the medical institution, educational system, and legal structure of society" (p. 41). She expressed deep concern over how these institutions shape knowledge that society often adopts as truth. In her autoethnography, Zibricky employed an active voice and leveraged her insider perspective to center her inquiry. This approach exemplifies how autoethnographies enable researchers to construct new meanings and interpretations of their experiences. As a first-time ethnographer, I had to rely on other ethnographies to understand and learn how to conduct my own ethnographic study. Zibricky's work gave me the basic methodological structure to get started with my own study.

The Fatal Flaw

In a self-narration, Sparkes (1996) aligned himself philosophically with autoethnography and connected the personal with the cultural, stating, "I attempt to take you as the reader into the intimacies of my world. I hope to do this in such a way that you are stimulated to reflect upon your own life in relation to mine" (p. 467). His article explores how specific narrative forms can be used to examine the reflexive relationships between body and self over time, fusing the personal and the societal.

Sparkes draws upon moments from his narrative to explore the emotional dimensions and consequences of an interrupted body project. He considers what this meant for his past, present, and future selves. His narrative focuses on his current 40-year-old, white, heterosexual, middle-class, male, "failed" body, and memories of an earlier elite, performing, working-class body that housed a "Fatal Flaw"—a chronic lower back problem that prematurely ended his involvement in top-class sport.

As a professor, Sparkes described how the early stages of his autoethnographic writing were shaped by assumptions about proper academic work. He initially "felt the need to add something to the story to signal it as scholarship" (Ellis & Bochner, 2000, p. 28). His original draft contained a personal story framed by solid sections of theory. However, as he gained confidence in the value of sharing his story, he focused more on the narrative itself, weaving theoretical content into it where needed. The published version reads as an intelligent, personal, and emotional story supported by sociological knowledge.

Sparkes (2000) enriched his narrative by incorporating various data sources, including medical diagnostic test reports, reconstructions of conversations, newspaper selections reporting his athletic accomplishments, and excerpts from his personal diary. In his later analysis, he presented reviewers' comments on his manuscript, revealing diverse reactions to this research genre—from rejection as scholarship to calls for less theory and purer storytelling.

Sparkes's experiences of injecting personal narrative into traditional academia demonstrated scholars' varying readiness to accept this method, offering future autoethnographers insights into successfully attempting the approach. In his 1996 work, Sparkes used diary excerpts to express hatred and anger towards his "fatal flaw"—the lower back problem that stripped him of his love for sports. He found his identity as a male athlete and sense of masculinity lost. He acknowledged building his life around this flaw, "to build the shell of muscles to protect him from who he was and who he wasn't." This shell-building became an embodied cycle of events that increasingly shaped his life (p. 20).

As I read Sparkes's narrative, I felt deeply engaged and understood his experiences. I, too, had encountered a "fatal flaw" that had disrupted my plans and sense of self, leading to a profound sense of loss in my own femininity. More specifically, Sparkes use of personal excerpts from his diary to express hatred and anger towards his fatal flaw enabled me to see his role as researcher where he focused upon an interrupted body project and its impact upon his relationship to past, present, and future selves. This gave me the idea to deep dive into how I now viewed my own femininity. I also found Sparks use of reflexive relationships insightful on how his own perspective shaped the understanding between the body and self. This perspective changed over time in ways that fused the personal to the cultural. In sum, this narrative best aligned with my goals and objectives to my study. It provided the best example of data collection, use of methodology and how to analyze and display data.

Using Celebrities to Teach Autoethnography

Scott (2015) describes an assignment in a qualitative research course that uses autoethnography to offer insights about popular culture and to map how identity is formed through cultural interactions. The main objective of this assignment was to guide students from recalling memories of a celebrity, to conducting an autoethnography of how these memories shaped their sense of self, and finally to discussing these interpretations face-to-face with peers. Scott (2015) explains how she taught autoethnography to achieve these goals, drawing on Ellis's concept that "autoethnography refers to the writing about the personal and its relationship to culture. It is an autobiographical genre of writing and research that displays multiple layers of consciousness" (p. 37).

According to Scott (2015), the first part of the assignment, the "interaction," requires students to "place [themselves] in the center of the text" (Giorgio, p. 407) and analyze their self-understanding through their responses and reactions to a celebrity they know only through mass media exposure. Students quickly realize how their grasp of ethnographic field notes and thick description translates easily to autoethnography (Scott, 2015, p. 507).

For the second part of the assignment, Scott (2015) asks students to choose one or two critical-cultural studies theories—such as Gender as Performance (Butler), The Beauty Myth (Wolf), Unbearable Weight (Bordo), Eating the Other (hooks), Hegemonic Masculinity (Connell), Compulsory Heterosexuality (Rich), and Compulsory Able-Bodiedness (McRuer)—and use these theories to analyze the interaction and its cultural significance in a column marked

"My Interpretation." This step follows Giorgio's (2013) instructions to "attend to the cultural and political tensions between lived experiences and their meanings and ethical concerns about representations of self and others" (p. 407). This two-step autoethnography separates the story from the analysis, allowing students, as new researchers, to view their stories as data to analyze, to become their own participants, and to recognize themselves as bodies telling stories entangled in cultural meanings that both facilitate and restrict their interpretations and responses (Scott, 2015, p. 507).

In the third part of the assignment, Scott (2015) assigns students to groups to read their stories aloud and provide personal analyses. Their conversations gain momentum as they exchange memories of their reactions to celebrities experienced via mass media and how these shape their self-understanding. This first encounter with peer response is in-person rather than through anonymous written evaluations, avoiding detached, impersonal critique. This classroom interaction was inspired by Gingrich-Philbrook's (2013) assertion that autoethnographers must "[navigate] how others encourage them to understand themselves . . . to both see another interpretation but also [resist] the less useful understandings by writing back against the grain of the taken for granted" (p. 617). In these exchanges, students access a researcher's standpoint as they observe how their interpretations of popular culture identities merge and diverge with one another (Scott, 2015, p. 508). The students then apply the fundamentals of the theories they chose in the second part of the assignment. In their groups, students work together on interpretations, using their shared familiarity with mass-distributed popular culture data to trace how their personal experiences, contexts, values, and understandings influence their interpretations of a familiar personality, gaining clarity through comparison.

During this third part of the assignment, Scott (2015) shares her own autoethnography about a conversation with a director/professor in her 1998 theater arts class during her undergraduate studies. She describes his reaction upon learning she was permanently disabled when he inquired about her limp. Scott discusses her interaction and interpretation of how she could "pass as normal" before her disability became common knowledge, but then it became a permanent feature that brought this role to her director/professor's mind, who thereafter only saw her as a disabled actor. Scott (2015) describes her use of McRuer's concept of "compulsory non-disabledness," explaining how her abnormality surfaced in the reiteration of compulsory non-disabledness and was marginalized by naming it. This experience became foreign and startling to bodies marked as "normal" and those marked by disability that ascribe to the medical model's view of bodies as diagnosable machines that break down and run inefficiently. Scott never played an non-disabled role again, as her limp became her defining feature that needed to be explained in the script, reinforcing the compulsory non-disabledness that demanded her presence be the manifestation of "not normal" (Scott, 2015, p. 515).

The assignments were separated into three separate phases: finding a celebrity, implementing theory, and group work exchange. Scott also shared her own autoethnography and reflection to the class. For my own autoethnography I followed two of these phases (omitting the groupwork and celebrity element). Through Scott's article (2015) I saw how autoethnography described cultural tensions that enable and constrain daily interactions through which we come to understand others and ourselves. For example, I was reminded of a similar experience of how being labeled disabled changes people's perception of who you are with this newfound awareness of being disabled. I also discovered McRuer's (2006) concept of "compulsory non-disabledness," which is a societal expectation and pressure to conform to the standard of being physically able bodied and treating it as the norm by viewing disability as a deviation. McRuer argues that this concept is not based on biological reality but rather on social norms and expectations that elevate non-disabledness as the ideal state. Within the class Scott defined researcher-reflexivity as “the realization that the event of collecting data as a qualitative researcher is an act of meaning-making, with bodies entangled in cultural discourses that value some identities over others, with shared understandings always vulnerable to reinterpretation” (p.506).

Autoethnography Supercripping the Academy

In an autoethnography, Lourens (2021) explored her experiences as a visually impaired lecturer at the University of Johannesburg, South Africa. She dissected her "supercripping" performances within the academy—her continual efforts to conceal her disability despite being included in this space. By describing her attempts to hide truths about her disability, Lourens revealed the cost of these performances and discussed the importance of open, responsive relationships in the process of "coming out" (p. 1207).

Lourens began her article with a brief history of her experiences in academia, which were—and continue to be—marked by numerous deliberate efforts to counteract disability-related stereotypes. She rarely complained about difficulties caused by her disability, thus concealing any trace of vulnerability. Lourens embodies what disability scholars call a "supercrip"—a person who has seemingly overcome their disability, claiming to be "as un-disabled as one can be" (Watermeyer, 2017, p. 153).

In her autoethnography, Lourens (2021) narrated three distinct experiences as an academic with a visual impairment. She critically reflected on these experiences, dissecting the intricacies of living with a disabled body in an environment designed for non-disabled employees. She took an in-depth look at the external milieu of higher education and the ways in which her body does not fit within this academic space.

In the first story, Lourens recounted a conversation with a university colleague who often forgot about her visual impairment because she never asked for help. The second story detailed her social interactions with new colleagues and her fear that these newfound friends would ignore her once they discovered her disability—an experience from her previous university position. The third story described her reaction to a promotion that would increase her workload, potentially exacerbating difficulties related to her disability. Each experience was described in detail, along with her reactions and the interplay between theory and context. These recollections evoked painful memories from her childhood and adolescence of feeling different, ashamed, and excluded.

Lourens believes her fears of being seen as a person with a disability stem from early messages about what is acceptable for a disabled person. Growing up with a visual impairment, she encountered the ideal of independence prevalent in the non-disabled world and learned that disability is often framed as a binary concept. Lourens (2021) wrote:

> I could not admit that I was different– not even to myself. And this is exactly where I positioned myself within the academe– as a member of the non-disabled community. To my mind, I needed to tone down, to gloss over any trace of my disabled self to fit into the academic space and the world at large (p.1212).

Lourens (2021) chose autoethnography for its ability to examine how contextual factors—culture, society, and relationships—shape or fail to shape experiences. This method allows for deep introspection, accessing thoughts, feelings, and bodily sensations connected to experiences. It blends vivid, emotive memories with broader social and cultural aspects, transforming experience into a rich, contextual story (Adams, Holman Jones, & Ellis 2015; Denzin 2013; Ellis 2009). Through writing, autoethnographers often gain a deeper understanding of their own life stories (Bantjes & Swartz 2019). Lourens (2021) aimed to shed light on broader social inequalities and hoped writing would help her embrace the vulnerable, unspoken aspects of her existence. She employed a "hybrid approach to autoethnography" (Stanley 2015, 150), balancing analysis and evocation. She used theory and context to interpret her memories and experiences as a disabled academic, making sense of them through critical disability scholarship. She examined her experiences through the lens of higher education in South Africa (Lourens, 2021, p. 1209). This process allowed her to work through painful memories and gain meaningful insights to inform her work as a university lecturer.

After three years as a university lecturer, Lourens realized her experience differed significantly from her colleagues'. While they all faced typical academic demands, she also navigated a world not designed for her disability. Her reality was both physically and psychologically exhausting. Eventually, she decided to "come out" about her disability to her department head, finding unexpected acceptance. This experience gave her the courage to be openly disabled in academia, fostering a sense of safety and security. Lourens' (2021) use of thick descriptions on how she incorporated literary techniques like vivid descriptions, dialogue, and narrative storytelling to engage readers and convey the richness of personal experience was a model I used in my own work Here, I was connected by the same feelings of being exhausted and frustrated by participating in an environment that does not support disability. More specifically how she made sense of her experiences as a visually impaired university lecturer, her continual performances of non-disabledness, and her rational for concealing truths around her disability. Like Lourens' experiences, I, too, found my treatment changed when people found out my disability was permanent.

Concluding Thoughts Regarding Autoethnographies and Disability

Autoethnography's focus on the interconnectedness of inner and outer realities, with personal experience at its core, makes it particularly effective for communicating disabled embodiment (Adams, Holman Jones, and Ellis 2015; Richards 2012). It creates a space to untangle the complex relationships between a disabled body and a world not designed for it, revealing experiences of the physical body, the external world, and the fit—or misfit—between them. As Marks (1999) notes, it is a method that "recognizes the importance of examining the interrelationship between embodied subjects and complex social and psychic relationships" (ix). These approaches give disabled authors tools to voice nuanced narratives of their embodied experiences. Many autoethnographers write not only for others but also for themselves (Adams, Holman Jones, and Ellis 2015; Chang 2008; Maseti 2018). Autoethnography celebrates emancipation, welcoming voices that break silences and highlight the dissonance between disabled bodies and their surroundings (Gale and Wyatt 2019; Richards 2008, 2012).

Autoethnography powerfully expresses lived experiences of specific cultural phenomena (disability) because it creates a space to untangle the complex relationships between a disabled body and a world not designed for it. Incorporating the three distinct autoethnographic studies offered valuable guidance, insights, and exemplars for my own research. By examining these studies, I gained a deeper understanding of the autoethnographic methodology and its application in academic contexts. Particular attention was given to the researchers' language choices and narrative techniques, as these elements significantly influenced my approach to crafting my own autoethnography. I drew on the researchers' experiences with disability to develop a nuanced understanding of how to effectively communicate personal experiences within a scholarly framework, balancing the intimate nature of autoethnographic writing with the rigor expected in academic research.

Currere within Autoethnography

My journey to better understand my life post-stroke started with currere before it became an autoethnographic study. This curriculum theory-informed process of narration becomes a vehicle for understanding the nature of the self. Pinar's (1975) concept of currere, or "curriculum of life," seemed to be a natural fit with the storytelling traditions of autoethnography mentioned above. Whereas currere examines an individual's perspective on a concept, autoethnography extends currere by employing the individual voice in dialogue. Moreover, currere is a strategy that examines an individual's perspective on a concept, and autoethnography extends currere by exploring how life histories affect the meanings they give to experiences in a social and cultural context.

Currere allowed me to turn inward and examine my experiences, towards a deeper understanding of myself and my outer world. I used this method to travel into the past to reexamine my memories of the post-stroke experiences in the rehabilitation hospital, where I stayed for six months. Pinar posited, "currere is a reflective cycle in which thought bends back upon itself and thus recovers its volition" (p. 517). With this idea in place, the question of self-renewal was associated with a heightened consciousness and cultural revolution, with a shift from outer to inner by exploring a systematic search of our inner experiences and our use of the public world. Examining the public world's materials and our uses of them through their structures, designs, and evaluation has great potential. This process discloses new structures by bringing to the surface assumptions and awareness of the experiences by naming the old assumptions.

Pinar's idea was to step back and peer into the darkness by exploring the blind spots through a series of four steps or stages: "regressive, progressive, analytical, and synthetical." The regressive stage is to return to the past, walk around and observe your past lived experience, record what is observed, and by recording this observation, bring this process into the present. In the progressive stage, the student of currere brings what was revealed from the past into the present while projecting these experiences into potential future scenarios. In the analytical stage, the student of currere puts the knowledge gained in the regressive and progressive stages aside to find the connections and themes that have emerged. In the synthetical stage, the student of currere collects all the insights from the first three stages—the "regressive, progressive, and analytical"—to create a collective whole. In this stage, the student of currere looks for common themes or categories and within such themes focuses on the self and point of view. The student of currere is encouraged to take their point of view, examine it, and juxtapose its relation to one's psychological, physical, and biographic conditions (both public and private).

Moore (2013) illustrated that currere is the Latin verb meaning "to run" in the way a current runs or flows. Curriculum is a noun that springs from this root and means: a running, course, career (p. 12). The goal here is to explore where you have access to and had the most or least amount of agency. Moore (2013) asserted that "currere offers an opportunity to go back to the beginning, project into the future, and then, purposefully and intentionally examine the in-between space" (p. 12).

Data Collection and Analysis

The currere process provided a strategy that allowed me to re-experience or re-remember older memories of conversations that I had with people about stroke and disability, which provided me with a new perspective. I used these older memories for my autoethnographic data. I wrote down my thoughts, feelings, and observations, which included significant moments, emotions, and insights in a reflexive journal I kept. This journal ensured a thorough account of past events, reliving past experiences and examining them from a present perspective. In my journal, I documented my observations and interactions that were relevant to my experiences, which included details about the environment, conversations, and my own reactions by first writing the narrative with dialogues within each snapshot memory, then providing extended and detailed context to memory. I then looked for patterns and themes. Next, I analyzed my situation/topic and explored the root cause, giving insights into my interpretation. I documented my biases, assumptions, and made note of them in a reflective journal for my interpretation. I used my reflexive journal to record the data gained from my self-interview with my currere notes as a self-interview. Anderson and Glass-Coffin (2013) suggested constructing a "dialogue between one's past and present selves" through a self-interview by reconstructing "scenes from one's own life experiences" (p. 69). The self-interview allowed me to examine my two selves—pre-stroke and post-stroke. Data came from my recorded observations, interactions, and a self-interview that were written and recorded in my reflexive journal.

This writing and reflecting on my personal post-stroke experiences using the method of currere allowed me to turn inward and examine my experiences, towards a deeper understanding of myself and my outer world. I used this method to travel into the past to reexamine my memories of the post-stroke experiences in the rehabilitation hospital. I decided to use and start with my rehabilitation hospital because it helped to transition into my currere experience in the rehabilitation hospital and then again into the start of my first snapshot memory at the rehabilitation hospital. I felt this physical location would be the best place to signal an ending and a beginning for my experiences.

For the currere method, I went back into that space and place and wrote down everything that I saw. I then let it marinate while I moved into the next stage, which is to bring the past into the present of what I learned and project it into a future scenario. I then let it marinate while I moved into the next stage, which is to bring the past into the present of what I learned and project it into a future scenario. For me, I used a form of meditation and breathing exercise that helped me to return or reenter into the past. For example, I placed a piece of paper at my feet, I followed the outline of the paper breathing in on the sides and breathing out on the top and bottom, after this I spoke into my Dragon speech software headset and recorded my findings. In each experience, I returned to the past, brought it into the present to interpret, then into the future to project how it could be different or a better scenario. Through the currere process, I started to sense what I would later understand as ableism, a societal prejudice towards disability that requires fixing or curing, and how in each memory people projected these ideals onto me in each experience by making decisions about me without me; what I thought or wanted got lost in the chaos of my stroke diagnosis, treatment, and recovery.

It was through my currere writing, I recalled other memories I had, more specifically, conversations with people on their perceptions of stroke and disability. I found these new recovered memories rich with insight on my experience of my past non-disabled self-compared to how other people viewed disability. I decided that I could tease this idea by exploring how my dual experience as an non-disabled person prior to my stroke impacted my experiences as a person with a disability after it. I wanted a method that would best exhibit my memories. I found that autoethnography, an extension of the currere process, allowed me to critically self-reflect on past experiences. Autoethnography, like currere, enabled me to travel back into the past using the same meditation and breathing exercise, bring the past to the present and interpret my findings, analyze relationships between self and others, compare with social science constructs and frame with theories. As autoethnographers, we examine our personal lived experiences in reference to the experiences of others, purposefully commenting on culture and cultural practices to "illuminate more general cultural phenomena" (Jones, Adams, & Ellis, 2013, p. 23). According to Richardson (2000a), strong reflexivity is essential in autoethnography as autoethnographers seek to show "two selves"—the "before self" and the "after self" that emerges after a transformational experience (Bochner, 2000).

I looked for rich, detailed, and personally reflective information drawn from people's conversations on their perceptions of stroke and disability. Did their current knowledge mirror my former non-disabled self ? Would this impact the way I saw my new disabled self ? I wanted to examine how my dual experience as an non-disabled person prior to my stroke impacted my experiences as a person with a disability after it. Did these experiences reflect my findings with the five snapshot memories I encountered during this study?

My personal experiences and perspectives were an integral part of the research. I used writing as a tool to construct knowledge for my personal use, because writing involves cognitive understanding as we process our lived experiences.

As data sets emerged, I employed an editing analysis style, which involved deciding on the content and structure of my stories and how they related to my cultural analysis, by comparing my personal experience to existing research. I decided to use my snapshot memories in chronological order, starting with the first one after I was released from the rehabilitation hospital and on to a five-year span. After I finished recording my recalled memory, I would go back and **bold** (code) a phrase that stood out or impacted my memory. Next, I connected this memory with a past study or a theory that would support my experience. Finally, I would go back and self-interview with my past self and have a conversation with myself.

I reflected on the events and actions, analyzed them, and made connections between my specific situation and the larger social world. The primary source of data collection for this study was from my currere notes. I used reflexive journaling with my currere notes as a self-interview (Anderson & Glass-Coffin, 2013) to ensure a thorough account of past events. In a self-interview, autoethnographers try to construct a "dialogue between one's past and present selves" (p. 69), reliving past experiences and examining them from a present perspective.

As data sets emerged, I employed an editing analysis style to interpret the qualitative data from my autoethnographic writings. This approach involved carefully reading my work to identify meaningful fragments. I then reviewed these fragments to develop a categorization scheme. These codes helped sort the qualitative data, revealing structures and patterns that enhanced my understanding of thematic categories (Polit & Hungler, 1999). Lastly, I labeled and categorized the data in preparation for analysis.

I approached my experience analytically by first separating the findings into smaller topics, then trying to understand the cause-effect relationships between variables and answering questions of why and how. I used descriptive coding by assigning bolded statements to sections of my experiences to capture the important nuances of my experiences in a four-step process:

1. I read the data and identified the topics that surfaced.
2. Created codes for each topic.
3. Coded excerpts according to topic.

4. Collected all the excerpts together that are related to each descriptive code.

This approach involved carefully reading my work to identify meaningful fragments. I then reviewed these fragments to develop a categorization scheme. For my coding process, I used inductive coding. I read the data, identified initial codes from the data, and developed categories and themes based on recurring patterns and then made interpretations.

To interpret data, autoethnographers need to employ narrative analysis techniques, which is to analyze their stories by paying attention to key events, turning points, and significant moments that revealed insights about their lived experience. According to Ellingson and Ellis (2008), an autoethnographer must "integrate theory by using theoretical frameworks to interpret them and connect to personal narrative to broader social and cultural issues, comparing their experiences to provide context" (Ellingson & Ellis, 2008, p. 449). Established research in the field is used to identify similarities and differences to provide context. One must maintain reflexivity by constantly reflecting on their own biases, assumptions, and positionality as a researcher, as they inevitably influence interpretation of data. Reflexivity can be accomplished by actively reflecting on one's own behavior through a process called self-explanation. Ellis, Carette, Anseel, and Lievens (2014) expressed that self-explanation is an active process of gathering, analyzing, and integrating data using questions that might prompt self-explanations like "how did you contribute to the performance observed in the experience" and "how effective were you in this experience," but also more direct questions such as "why" (Ellis et al., 2014, p. 68). Direct questions provide specific and internal explanations, making the reflection process more effective.

I relied on data interpretation from my own imagination and intuition as I negotiated my inner world's relation to the outer world. This analysis and interpretation involved my attention shifting back and forth between myself and others, between the personal and social context. I used a zoom-in, zoom-out approach—zooming in for select details and out for the big picture. I connected and compared my experiences to others' similar post-stroke experiences, structuring them with theory and other studies. I broadly contextualized and compared these to other social science constructs and ideas. In my reflective journal, I documented my biases, assumptions, and made note if my personal experiences influenced my interpretations.

In chapter four I begin my story by describing the morning I woke up feeling off to all the experiences I have had from that morning up until now. In this, I used my currere experience at the rehabilitation hospital to my first autoethnographic snapshot where I return to the same rehabilitation hospital for a stroke survivors support group where I begin to illustrate the interactions, that I shared between myself and others. In each snapshot memory I used narrative storytelling to create vivid descriptions of my personal experiences so that I could connect to broader cultural, political, and social meanings and understandings. I used thick description to detail my experiences by recording my thoughts, emotions, and motivations. A reflection section followed each snapshot, following the example of Humphreys (2005). I reflected on what each scene meant to me and how it connected me to the social world of disability.

Conclusion

This chapter has provided a comprehensive overview of the methodological approach and theoretical framework that guided this autoethnographic study. The social constructivist paradigm has been chosen as the epistemological foundation, recognizing that knowledge and reality are constructed through social interactions. This framework allowed for a critical examination of how disability is socially constructed and how it shapes individual experiences and identities.

The chapter has also outlined the key principles and methods of autoethnography, emphasizing its qualitative, self-focused, and context-conscious nature. The methodological tenets, including the use of personal experience as primary data, deep self-reflection, and linking personal experiences to broader cultural contexts are outlined as elements that were crucial in exploring my personal journey of losing non-disabled privilege and gaining insights from a new disability identity.

Furthermore, the chapter has delved into the concept of autoethnography as a constructionist project, exploring how it bridges dichotomies in social constructionism and enables critical reflection on taken-for-granted aspects of society. This approach will allow for a rich and complex understanding of my experiences within the broader cultural and social context of disability. As the study progressed, these methodological and theoretical foundations guided the process of data collection, analysis, and interpretation. The autoethnographic approach informed by currere facilitated a deeply personal and reflective exploration of my experiences, while also connecting these individual insights to broader societal understandings of disability.

Chapter Four: Findings

In this chapter, I start by describing the morning my stroke began and then expand on the two currere experiences at the rehabilitation hospital. Following this, I move into the snapshot memories. In each snapshot memory, I used narrative storytelling to create vivid descriptions of my personal experiences so that I could connect to broader cultural, political, and social meanings and understandings. My story is about describing the morning I woke up feeling off to all the experiences I have had from that morning up until now. In this, I used my two currere experiences at the rehabilitation hospital and my first autoethnographic snapshot where I return to the same rehabilitation hospital for a stroke survivors' support group where I begin to illustrate the interactions that I shared between myself and others. A reflection section followed each snapshot, following the example of Humphreys (2005). I reflected on what each scene meant to me and how it connected me to the social world of disability.

I tried to learn from my experiences and find meaning in my six snapshots, followed by a reflection section. Autoethnographic analysis should occur in pieces after the story and reflections have been written (Bochner & Ellis, 2016), so the analysis section of this work weaves together the reflection and analysis section of each snapshot. As I reflected on and analyzed my experiences, I tried to answer the following self-interview questions:

1. How has your life changed since your stroke?
2. What have you learned?
3. Are there aspects in your pre-stroke life that you took for granted?
4. What do you want people to learn from your study?

The Long Day

Early morning in late February, my alarm shocked me awake, and it was still dark outside. My dog, Barbosa, was ready and excited, anticipating our morning walk before I got ready and went to work. My head was pounding, and I brushed it off, deciding it was from last night's drinking with my neighbor next door. My eyes were blurry; I rubbed them and blinked until they were clear. It was cold outside—I could see my breath. Barbosa felt the cold as well and was frisky. The streetlights and the neighborhood lights all had a rainbow light around them like a halo. I rubbed my eyes and blinked again. I didn't feel good. I sped up our walk and hurried back home to take pain medicine for my now massive headache. I drew a bath and gently sank into the warm, inviting water, immersing my head completely under the water. It was in this space, underwater, where I felt better, a momentary relief. The sun was up as I drove to work.

My eyes were better now that it was light outside; however, inside, the iridescent light returned, only now it seemed that I was viewing my world through lace. In my office, I realized that something was off and called my parents for advice. My dad came to my work to pick me up and take me to an ophthalmologist. At a second ophthalmologist appointment that same day, I couldn't think or speak as my headache was unbearable. We were talking to the doctor, and he handed me a prescription sheet. I reached out for the prescription with my left hand, and I dropped it. I remember thinking, "That's strange." The doctor stopped talking to help me pick up the prescription and asked, "Are you okay?" Back at my house, my dad suggested that we go to their house and property. I started to stumble getting my things ready to go out to my parents' place. My dad looked at me and told me, "We're going to the ER!" I think my face was starting to droop. In the ER parking lot, my leg stopped working, and my dad picked me up and carried me the rest of the way. Inside, I was rushed past triage into a room with a curtain where men and women rushed about me asking questions and monitoring my vitals. The neurologist on call stepped in and told us that I had a stroke and that I did not need a craniotomy. "A WHAT!?" I did not even know what that was but "okay, thank you." From this point on, I do not remember much. Apparently, I stayed in the ICU for a week (so I am told) before I was transferred to a rehabilitation hospital where I stayed for six months.

The Rehabilitation Hospital

It was a bright sunny morning, my room was filled with bright light, and I had just had a shower and was dressed for the day. I remember feeling relaxed and content as I inhaled my familiar earthy smells of amber, sandalwood, and patchouli because my parents brought my products from my house. I was happy to have my cherished familiar smells of my own products instead of the sterile products that the hospital provided. I was sitting in my wheelchair having breakfast when the nurse came in to administer my morning meds. I was at the stage where I was taking more initiative in my treatments and asking what medications I was taking and why. Most of the medications were for stroke prevention, and I did not question them. But on that morning, the nurse said that one pill was an antidepressant. I remember getting agitated and asking why I was getting this without being consulted first; her reply was that "I was severely depressed, and I would not look at people when they were talking to me or at me."

Several weeks later I was wheeling down to my speech therapy session at the rehabilitation facility. I was at the point in therapy where I could take myself to sessions, instead of being escorted; everyone knew me, and I remember feeling happy because, the day before, I had been accepted into the Curriculum Studies doctoral program. I wanted to share my good news with everyone. On my way to speech therapy, I said hello to everyone I met. The first person I told was my speech therapist; however, the reception received was not what I had anticipated. The therapist picked up a book on neurology and told me to read it aloud. I did what I was told and struggled to pronounce the unfamiliar terminology. The therapist said, "You are not ready to start a doctoral program. You cannot even read from this book. What makes you think you can start a doctoral program?" My happiness changed, and I chose not to share my good news with anyone else, fearing a similar reaction as the speech therapist.

The experience with the nurse felt like a personal attack—one I was not consulted with or even asked if I wanted to be on antidepressant medication. The nurse's words repeated in my mind, and I felt agitated and patronized for the rest of the day. The next morning, I refused to take the medication, but my decision was overruled, and I was forced to take it every morning. When I told a friend about what had happened, she said it was probably a good temporary thing because I was stuck indoors, and my ordinary routines had been altered. Why did the other medications not disturb me? Why did the antidepressant enrage me? I was told how I should feel after experiencing a stroke. A better and more productive scenario would have been the nurse asking if I thought that I needed or wanted medication. Instead, my freedom and choice were taken away.

The experience with the speech therapist haunted me, as I would soon find out during my studies, by rocking my confidence. I had not planned on starting my doctoral program until I had finished my outpatient therapy and recovered more. The speech therapist seemed to be establishing dominance by belittling me. As a patient in a rehabilitation hospital, my job was to recover, and the speech therapist's job was to help reach my desired goal. When someone belittles you and says that you are not ready, you start to doubt yourself and believe what was said. I was left sad, angry, and defeated.

The nurse told me how I should feel, leading to depression. The speech therapist told me that I was not ready to be a doctoral student, leading to self-doubt. In both encounters, a better and more productive scenario would have been the medical professionals asking my thoughts, wishes, and desires for moving forward in my treatment. Instead, I was made to feel that my new disability would prevent me from being a successful student outside of the rehabilitation hospital. Now, looking back, I did see some truth in what they were saying to me, but I should have been consulted first and been given some control. Both encounters at the rehabilitation hospital stripped me of agency and placed me in a position of authoritative submission. Reflecting on these encounters, I realized my treatment had changed since my stroke and that this treatment would never have occurred if I was still a non-disabled individual.

My pre-stroke life consisted of teaching English to international students at my university, going on long hikes with my beloved dog (Barbosa), drinking with friends, and living in my two-story townhouse. I was independent, self-sufficient, and happy. My stroke took all this away from me; I had to stay in the rehabilitation hospital for several months on their schedule of when to bathe, dress, eat, sleep, and attend therapy. During these months, I lived an institutional existence. During this institutional existence, I was fine conforming to their schedule if it helped me to recover. My experience in this rehabilitation hospital did allow me to recover but at the cost of feeling depressed with self-doubt towards my future graduate studies. These two experiences helped to uncover how and why my agency was taken away.

To help my understanding of my two experiences at the rehabilitation hospital, I needed to find an academic structure that would best demonstrate and provide understanding to my two experiences of power dynamic shift and loss of agency. I discovered the concepts of ableism and Othering, two concepts grounded in critical disability theory. Did my two experiences at the rehabilitation hospital display implicit (unconscious) attitudes towards my disability? I know that I too had an unconscious bias about disability before I was disabled, which was conditioned and taught through society's view of the disabled. I have learned from these two experiences that they have each placed their own ableist attitudes onto me. The negative effects of ableism have been socially and psychologically damaging for me as well as for other people with disabilities. In chapter five, I will discuss in more detail how these experiences combined with the literature in chapter two can give a greater understanding of what the experience of disability can be like.

It has been eleven years since my stroke and my two encounters at the rehabilitation hospital. I had not learned of disability studies or ableism while undergoing these experiences, but I did know that I was treated differently, and I did not like the feelings these experiences brought on. Only now do I have the language or labels that describe my feelings from these experiences. Did my new disability equate to a shift in the ways people saw me? The rehabilitation hospital was the first place I learned what it meant to be disabled. If a rehabilitation hospital treated me this way, I feared how society and the outside world would see me.

A Return to the Rehabilitation Hospital

After a few months of being back home and outpatient therapy, I returned to the rehabilitation hospital for a stroke support group. I remember feeling proud of myself for walking back into this hospital because before, I was wheeled out in a wheelchair. We all sat at tables arranged in a circle and watched a short segment on strokes; we then introduced ourselves and described the type of stroke we had and gave any helpful tips on how to better live with this condition post-stroke. When it was my turn, I explained my stroke to the group, but I did not have any helpful tips to share because this experience was still so new and fresh. One man described his stroke and gave his helpful tip to "go through the five stages of grief which are denial, anger, bargaining, depression, and acceptance." Because "the stroke had taken something away from us all," he explained. "Once you are ready, find yourself a hobby and get back out in your world; my hobby is antiquing, which is to go shopping or looking for old antiques and then restoring the piece for sale or display," he added.

Apart from being the youngest person in this group, I learned that strokes affect people differently and each person has their own way of coping with a stroke. As the saying goes, "different strokes for different folks" holds true for us all. I also realized it's okay to be angry and depressed because I had lost a part of myself. And I was angry—I was angry at my body for failing me at an important time in my life of transitioning from teaching to starting a PhD program. I ended up losing my teaching position at my university as well as my freedom, independence, and agency. As for my hobbies or activities, I used to take long hikes with my beloved dog, Barbosa; now we take long walks around my property in search of squirrels and rabbits or even an armadillo, mainly for his interests, and to maintain a regular walking schedule for myself. Looking back now, I can see that I took these activities and hobbies for granted pre-stroke, an non-disabled privilege.

My parents drove me to the hospital and waited in the car until the meeting was over. I was nervous, anxious, and a little insecure, as this was my first time out by myself. I made a note about these feelings of nervousness, anxiety, and insecurity, as these were new.

I remember looking around at each person in the group, studying them as they introduced themselves to the group. I did not have anything in common with the people in this group, and I did not belong here since my limitations seemed to be less severe when compared to the others. Each person had a different experience and was at a different stage in their recovery. They also had more knowledge about the actual workings of a stroke; even the language they used felt foreign to me. I was aware my stroke recovery was going to be a long and difficult road. Listening to the group and hearing their stories of multiple years of post-stroke recovery hit me hard because I hadn't realized that my stroke recovery was going to be a lifelong journey. I thought because of my younger age of experiencing a stroke that my recovery time would be shorter and easier. Upon this new realization, I could feel my entire body shifting to discomfort and panic, and I wanted to cry. I looked down at the ground to avoid being seen by the group until I was able to compose myself again. I shared a table with a married couple; the man had experienced a stroke five years back, and his wife was his caregiver. I had not been out in public, apart from time spent with family and friends. I had to force myself and reacquaint myself with how to be social again. I remember telling myself to look at them in the eyes when talking and listening to them. I asked him about his limitations and thanked him for sharing his experiences. His wife spoke for him, and realizing that his limitations were in speaking, I felt bad about my question and began talking to his wife. She had made and brought a notebook organized with doctor appointments, rehabilitation schedules, and government disability claims. I was impressed with her organizational skills and was thankful that my dad was taking care of the paperwork part of my recovery.

I did not say much on our long drive back home because I realized that I did belong in this group, and I wondered if I would ever return to resemble even a small portion of my former self. My rehabilitation experience had already proved a different type of treatment because of my disability. How would the rest of the world treat me? Yes, I was scared, and I think that I had forgotten just how scared I was until now. I tried to maintain a sense of bravado to those around me, but deep down, I was scared because I could not outrun this. No, I could not outrun this literally, mentally, or physically. This new vulnerability was scary. I now had to turn and face the music and set out to become the new me by learning new ways to live.

Memories of My Father

One morning, my father and I were sitting at the kitchen table having our coffee. At this time, I was still living at my parents' house when I brought up my frustration and disappointment about my left arm still not responding to treatment. He looked at me with his stern stare, indicating for me to listen and not look away (a familiar stare I received when I was in trouble). "You got off easy, Stephanie. Think of all the people who are completely incapacitated by a brain or spinal injury and will never be able to live their previous lives," he said to me. "You are well on your way to an almost perfect recovery." A few weeks before this conversation, we all learned that my dad had terminal lung cancer. "You will recover from this and learn how to adapt and accommodate the loss of your left arm," he explained to me. Looking down into his coffee cup, he whispered, "I will not recover."

My father passed away two years later, but before he did, we were able to finish our morning conversation. My father and I had a very strong bond which was formed during my horseback riding days, in which he taught me that when **"you get bucked off a horse you have to get right back on"** — which could be applied to many life lessons and especially to my stroke and post-stroke experience — to stop my whining, get back up, continue on, and be thankful it was just my left side that was affected. He also said that "you had this stroke because you were the only member of our family who was strong enough to handle its effects." My father also instilled the importance of being independent and being capable of standing on your own two feet.

It has now been eight years since my father passed away. I only wish he could now see that I am living in my house independently, that he made happen, and getting closer to finishing my PhD. I have made great strides in my recovery and am slowly becoming more independent. Ten years ago, I was a carefree independent nomad. And now I had to rely on other people for everything; truth be told, I hated being dependent on people. In the beginning, my pride hindered my dependence on asking for help when I needed it. Now, looking back at these memories, I realized that I am more confident, and when I need help, I ask for it, and that is okay. I have learned people want to help. I have also learned new ways of living by reinventing new ways of doing things that work for me. I know that my dad would be proud because I did get bucked off, and I got back on and learned how to be independent again, able and capable of once again standing on my two feet. Well, my two feet with a brace.

A Memory of Misunderstanding

"What the heck happened to you, girl?" a woman shouted at me from the waiting area of my local pharmacy. "Let me guess, you had a skiing accident and broke your leg?" After checking in, I sat next to her to explain my limp and need of a cane. "No, I had a stroke two years ago, which caused my left side to become paralyzed," I explained to her. She looked at me and said, "You're way too young for a stroke—that only happens to older people." "The type of stroke I had was a dissection of the right carotid artery, which became loose in a coughing fit, which caused an ischemic stroke," I explained. I also told her about the other young stroke survivors I had met during my therapy sessions. "One woman had a stroke during childbirth, while another man had a stroke from a boxing accident—they were all younger than me," I explained. "I had no idea, and I am sorry this happened to you," she said to me. "Thank you, I'm still learning how to live and understand my new disability identity," I told her.

Later that day, I realized that my ruse of disguising my disability was up, and it was obvious that something had happened to me. However, my age created a buffer, leading people to think it was an athletic incident causing my limited mobility. I also remembered a similar experience with a fellow graduate student asking what had happened to me. Yes, strokes usually affect older people; however, strokes are on the rise for younger women, as demonstrated in my literature review. My age and my stroke have been difficult aspects to overcome, and it was even more difficult to find someone to relate to and to better understand this transition.

Age plays an important role for stroke survivors, as young and old survivors have different experiences and needs. These are attributable to the effects of stroke on age-normative roles and activities, self-image, and the young person's stage in the life cycle, especially family and work. As described in a paper by Morris (2011) in the literature review section, the psychological effects of stroke and the evidence for their occurrence were linked to reduced quality of life, associated with dependence, depression, being single, fatigue, and being unemployed. More specifically, survivors experienced loss of home, loss of employment, psychological paralysis, and problems fulfilling roles, for example, parenting. It was also fueled by the sense of being outside and invisible, which revolved around lack of information, lack of consideration of young survivors' needs, a shortage of age-appropriate activities, and their awareness of their invisible cognitive impairments. More than half of young survivors perceived themselves to have enduring physical and cognitive disabilities and were dissatisfied with life after stroke, and many experienced problems caused by paralysis due to fatigue and the invisibility of disabilities, which predisposed colleagues, family, or friends to discount, ignore, or deny the "authenticity" of the survivor's limitations. A limitation I, too, have experienced with a family member reacting to my consistent fatigue by saying, "You are always tired," which left me sad and frustrated at the time. Today I would respond by saying, "You would be consistently tired, too, if you had to navigate in a world that was not designed around you," which is both frustrating and exhausting.

I also noticed that when I explained that it was not a skiing accident, her inquisitiveness turned to pity—a similarity I found in both Lournes's (2021) autoethnography and Scott's (2015) autoethnography of a treatment shift in knowing that the disability is permanent. This made me both sad and angry because I did not want people to pity me.

Memories of Unfamiliarity

When my house was being built, I needed to apply for a special permit at my town's city planning office located on the second floor of an old historical building. This building did not have an elevator, nor did it have hand railings on the staircase. As a result, my mother had to help me climb up to the second floor. When we reached the office, we both pointed out the lack of accommodation for a disability. The man in charge of my permit request told us to call and he would meet us on the first floor to finalize this process. He also said, "You're right, I never thought about it in that light. I just climb up and down the staircase without thinking about others who cannot." What my mother and I both found fascinating was the fact this is inaccessible building had accessible parking out front.

This experience occurs often and is caused by a social construction of the disability identity, which needs increased knowledge in the awareness of its different kinds, values, and realities. If you are not disabled, you do not experience or understand the implications of a needed accommodation. For example, these barriers in the physical, attitudinal, communication, and social environment become a problem when there is inaccessibility of public structures.

As a newly disabled person, I must rely on provided public accommodations; this has become second nature for me and my mother as my caregiver. Before my stroke, I never thought about disability accommodations because this was not a part of my daily reality.

Ability privilege comes to mind as I returned to this memory, seeing how a seemingly simple task of climbing stairs became a giant trek for both my mother and me to reach our destination. As a participant observer, I made notes on other ADA public accommodations such as accessible parking with curb cuts and ramps, and accessible restrooms with handrails. Accessible parking was readily available in most parking lots; however, I found some parking spots were afterthoughts, as these spots were situated at a distance, which meant that I had a longer distance to walk. For example, the other day I was out and about in my town running errands, and I needed to go into a gas station/convenience store. The accessible parking spot, curb cut, and ramp were on the side of the building; however, there was a Reddy Ice storage unit blocking the sidewalk and, unfortunately, I was not able to enter this store. As for accessible restrooms, there was always one accessible stall available in public places. The man in charge of my permit and other non-disabled people, including my past self, will not see the need for public accommodation when it is not provided because it does not affect them personally. Able-bodiedness was a privilege that I took for granted for most of my life.

Memory of Vanity

After moving out of my parents' house, I finally moved into the house that was built around my disability. Some friends came out to help unpack and decorate my new space; these friends had been there with me since the beginning at the hospital and into the therapy sessions. I know they had their reservations about my living situation being in the middle of nowhere, rural Texas and away from the social nightlife scene. But I reassured them that this was the ideal place for me and my beloved dog, Barbosa, and plus I was over the nightlife scene—as I no longer drank alcoholic beverages, due to a forced sobriety with a medicine overload. That day as we went through all my treasures from around the world, I opened up about being embarrassed about my brace and the required use of orthopedic shoes with the children's plastic shoe ties I had to wear. "Don't you remember when you were in a wheelchair, and you could not walk?" one said. "Who cares, look at you now, walking around in your new house and working on your doctorate," the other one said.

I never knew that this disturbed me until I saw them in trendy sundresses with gorgeous leather sandals that day. I realize now that my sense of loss questioned my own femininity. I no longer felt attractive in my Western worldview of sexuality, of the male gaze, of objectification of my female self.

I think this bothered me that I could no longer dress myself up to look sexy, not that I did often before my stroke, but now, I must wear sensible shoes and easy-to-dress attire. I realize that not being able to wear anything you want at any time is an example of ability privilege. Through this, I also saw that I equated beauty through fashion. Looking back on this now, I was mourning my lost sense of beauty that I valued. Realizing this made me angry that I was still vain, because in the grand scheme of things, I felt that this was small and petty. Through this, I saw how my view of disability impacted my ideal of what I thought of beauty, because as a woman, I have learned that beauty is always valued. This valuation of beauty is learned and valued within our cultural context. Thus far I have learned that disabilities represent negative, less valuable figures in society. Societal attitudes contain implicit messages that can influence our self-concepts. For example, non-disabledness is preferred and disabled bodies have been positioned in opposition to the norm. Individuals with physical disabilities have been presented as flawed non-disabled people, by reducing them to objects of stigma (Goffman, 1963). Implicit messages can influence our self-concepts, how we view right and wrong, how we conceive of living a good life, how we view beauty, and how we perform and affirm identity.

Memory of Being Seen

A few years later, I was shopping at my local grocery store when a man in an electronic shopping cart approached me. "Did you have a stroke?" he asked. "I did—how did you know?" I asked him. "I can tell from the way your left arm hangs, as my ex-wife suffered from the same effect," he explained. "What happened to you?" I asked him. "Vietnam," he said. I thanked him for his service and asked, "You have been living with your disability for many years, does it get any easier with time?" I explained to him that it had now been six years since my stroke and that I was still learning and understanding what it means to be disabled. "You just take it day by day and you find new ways of doing things, and eventually it becomes second nature and a natural occurrence," he explained to me.

I found comfort in our conversation that day, and I felt like he was the only person I could truly relate to in my understanding of my disability. Looking back on my conversation with the wounded veteran and his positive outlook on life—his "you either adapt or die" mentality, I gained new perspective. I saw him several other times after our brief encounter, and we always managed to acknowledge each other and ask, "How goes it?" and one of us always says, "It's going."

Key Findings

In each section above, I provided a quote that embodied an experience from personal memories and interactions, which were drawn from various encounters and conversations I had in a five-year period. I chose these quotes for their rich imagery as well as their ability to help my readers make associations and connections to my personal experiences. Through these narratives, I gained insight, revealing how everyday interactions can expose deeper truths about disability, adaptation, social understanding, and societal attitudes. In chapter five, I will return to these quotes and expand my personal discoveries into larger theoretical concepts drawn from the literature review in chapter two by drawing larger conclusions about stroke survivors and their journeys.

"Different Strokes for Different Folks"

This quote represented that every stroke survivor's journey is unique. Through my support group experiences and personal journey, I discovered that recovery paths vary significantly based on the type of stroke, its effects, and the individual's circumstances. I have also learned new ways of living by reinventing new ways of doing things that work for me. Looking back now, I can see that I took certain activities and hobbies for granted pre-stroke, an non-disabled privilege. This quote also served as a powerful metaphor, which symbolized individual recovery and coping mechanisms. As stroke survivors, we were all on our own path in understanding and accepting our own unique forms of disability, a fundamental finding from my research. Through this reflection, I identified several key concepts that recovery paths vary significantly based on the type of stroke, its effects, and the individual's circumstances. This understanding challenges the one-size-fits-all approach to stroke recovery and highlights the need for personalized rehabilitation strategies.

My aim for these reflections was to give perspective for others to understand the unique nature of a stroke, by analyzing my personal experience to enhance a deeper understanding of the broader cultural phenomena of disability through stroke.

“When You Get Bucked off a Horse, You Have to Get Back Up on that Horse”

This quote stirred a memory of my father, which helped me remember to be strong—that I could get through the challenges of a stroke recovery by relying on past life's lessons. This quote also represented moving forward, fear prevention, and acceptance. Moving forward and learning to adapt were important key concepts for me during this time in my stroke recovery, and to try to understand and accept my new identity and my place in this new world of disability. understand that I struggled in the beginning to fully accept my newfound situation. As human beings, we all use different coping mechanisms to aid us in times of need. I found mine with a fond memory of my father and the lessons he instilled in me. In this section of my reflection, I opened up about hating how I had to be dependent on other people, only realizing now that it was not a sign of weakness to ask for help; instead, it was a sign of acceptance and a positive move into the future. This old cowboy logic was my go-to mantra when I felt sorry for myself and needed positive encouragement, which also brought me comfort. My aim for these reflections was to give perspective for others to

"You are Way too Young for a Stroke—That Only Happens to Older People."

This quote came from a woman at my local pharmacy, mistaking my limp and my walking cane for a skiing accident. Through our conversation, I learned that she knew little about stroke, which represented the common misunderstanding of stroke-like, age-related factors and the different disability side effects, which I came to understand was a common phenomenon that also included myself and my family. In this reflection, I realized that it was obvious that something had happened to me, and my younger age protected me. I did not mind that people asked me what had happened to me because it is important to understand about strokes if they are on the rise in women. I have also gained perspective on the reasons why I was always extremely both mentally and physically fatigued because I was now living in a world not designed for me.

I also experienced that when I explained the permanence of my limp and walking cane, the woman at the pharmacy's attitude changed to pity. I did not like how pity made me feel because no one wants to feel pitied. I realized that I needed thicker skin and to get over myself because it was more proactive that people understood about strokes.

"You are Right, I never Thought about it in that Light. I Just Climb up and down the Staircase without Thinking about Others who Cannot."

This quote came from a man at my town's city planning center where both my mother and I pointed out that their building was not accessible for people with disabilities. This was a common occurrence that I started to notice only after I, too, became disabled. Here I learned that my pre-stroke life and non-disabled mentality was like the man at my town's city planning center. This reflection represented people with disabilities not being seen and understood because this was not a reality for non-disabled people—it is a privilege that most people are unaware of until it is taken away, which also included me. My aim for these reflections was to give perspective and raise awareness on accessible and inaccessible spaces for people with disabilities.

"Who Cares? Look at you Now, Walking Around in your New House and Working on your Doctorate."

A friend said to me when I confessed to being embarrassed about my needed disability-friendly attire. Here, I learned that I was mourning my past non-disabled privilege of wearing anything I wanted. I also learned that I equated beauty to fashion. This reflection represented a loss in positive self-esteem from a conditioned societal notion of what beauty should be. This seemed to still be an non-disabled normative ideal from my pre-stroke self, and now I confess that this disturbed my now post-stroke self at being vain.

"You Just Take it Day by Day and you Find New Ways of Doing Things, and Eventually it becomes Second Nature and a Natural Occurrence."

This quote came from a wounded veteran who approached me, knowing that I had experienced a stroke. In this reflection, he explained how to live with a disability, which represented someone finally seeing me and understanding what living with a disability entailed. I had finally found someone who I didn't have to explain my situation to—someone who truly understood.

A Wider Picture

In terms of the larger contexts of my life beyond the above key quotes, memories, and reflections, I identified themes that impacted the way I came to understand my disability experiences. These themes consisted of a loss of agency, identity transformation, and the intersectional role that disability played in social assumptions and social interactions.

Loss of Agency

I experienced a loss of agency from the very beginning at the rehabilitation hospital where I was made to feel powerless in my choices and in my future situations. At the rehabilitation hospital, people controlled my situation while I was a patient there, which disturbed and disrupted my sense of pre-stroke self. My time in the rehabilitation hospital illustrated that I was treated differently, leaving me powerless, and at that time I did not know how to regain control over the situation, which was scary, as this was one of the first time as an adult where I did not have control over myself and my situation. For years it was difficult to make decisions or act because I did not believe I had the power to affect the outcome, but truth be told, I did not know how. Today, as I look back and reflect upon these experiences, I notice how with time and from experience I became more confident because I found a balance between my pre-stroke self with my post-stroke self, which was a trial-and-error journey. I saw and now understand that I could not approach moving forward in the same way I had done pre-stroke as my life had drastically changed. This change was a delicate dance of disability that balanced upon my past, present, and future selves, in which I needed to help transition into my new identity of disability. In this process of finding balance, I needed to develop a mindset that was flexible and could respond to unexpected circumstances. I also needed to understand my strengths, weaknesses, values, and what I could enjoy. I needed to take small steps each day and focus on progress rather than perfection. Above all, I needed to know myself and remind myself that change was a natural part of life—I was strong enough to adapt to this change.

I also noticed the need to rely on accessible public spaces and experienced a sense of powerlessness when there was an inaccessible space impacting my ability to proceed in my necessary public activities. This feeling of not having control in your own life was a horrifying experience, in which at times I wanted to give up. When my mother saw that I was beaten down and frustrated, she made the plan for me to use her as my non-disabled advocate. When my mother and I were out running errands in our town, as planned she would "run" in and handle my business when I was not able to. This new system my mother invented for me worked extremely well for us; not only was it efficient, but it also provided an awareness of our situation in our local community. Sadly, my mother is no longer with us and her presence has been missing for two years now. My mother's system is still in place—only now I call these places when I am out front and give them my payment information and they bring the items to my car. Today, I am more aware of the inaccessible places around my community; luckily, now I have a system in place. These experiences of my loss of agency illustrated that I could no longer approach my life as I had in my pre-stroke self. I needed to create a new set of skills, such as a process of finding balance and the system my mother created out in public.

The Disability Identity

Disability is not one universal experience. People with disabilities do not have one shared lived experience, and they and their families have a variety of needs. I, too, discovered this concept in my return to the rehabilitation hospital for the stroke support group, learning strokes were not a similar shared experience. I was thrown into the world of disability where I had to learn how to navigate this new culture of the language, the geography of the land, and what I could and could not do. I remember thinking that I was thirty-nine years old, and I would have to relearn everything as I was now a blank slate and would start again from scratch. My experiences from my loss of agency and disability were formed from a trial-and-error process, time and experience, and the recycling of my set of adapted tools to aid in my identity transformation. In my research, I have learned that disability can be expressed in different ways, depending on a person's culture, experiences, and relationship to their disability. For example, a person's identity can also be tied to other social identities, such as race, ethnicity, sexual orientation, and gender. For me, my identity is a culmination of all my experiences, ranging from my childhood (when you get bucked off a horse) to my twenties assimilating into a new country's culture, to my 15 years of teaching both here and abroad. My many years of teaching abroad afforded me the privilege to move about independently with my own freedom—literally, the world was my oyster—a luxury I no longer possess because now my environment must support accessible accommodations. Today I have learned that I was not a blank slate because all my experiences have provided a solid base from which to now navigate my new disability identity.

Disability is said to be socially constructed, meaning that society has viewed people with disabilities as ill, dysfunctional, and in need of medical treatment. Having a disability meant carrying a stigma and deviating from the norm. Historically, society has viewed disability in a negative light, giving stronger preference to the non-disabled population, which preserved an ableist worldview, suggesting that people with disabilities should strive toward an non-disabled norm, reflecting society's perceptions that certain abilities are essential to fully function in the world, which has created implicit (unconscious) attitudes toward people with disabilities—an attitude, I discovered, I too shared.

The disability identity transformation is an embodied learning process that actively shapes the understanding of one's identity as a disabled person through direct, lived experiences within their own body, acknowledging the unique challenges and strengths that come with their disability, and integrating those experiences into their self-perception; by actively claiming and defining one's disabled identity through embodied knowledge and lived experiences. To accomplish this, one needs to recognize how one's body interacts with the world and navigate challenges presented by their disability daily, which informs one's understanding of self. Here, one must pay close attention to how one's senses are affected by their disability and how they can utilize them to navigate the world. Using personal experiences and embodied knowledge to advocate for accessibility and disability rights, shaping one's own narrative about disability.

My embodied learning helped me to develop strategies to navigate challenges and adapt to my disability in a way that was personally meaningful. I have been able to actively shape my own understanding of disability and gained a sense of agency in the process. I have also discovered that my environment and social interactions played a significant role in how I embodied and expressed my identity. Here, I found that my past learning experiences provided a solid base which I could use as a trajectory into my identity. From my experiences, I also discovered society's perceptions of disability that granted an insider's view of how disability is viewed in social assumptions and social interactions. The experience of disability and process of identity transformation is unique.

Social Assumptions and Social Interactions in Disability

Most non-disabled people never think about disability because it does not affect them directly, until it does. My pre-stroke self-did notice the accessible parking and the one larger accessible bathroom stall but never thought about what disability truly entailed until I became disabled. These inaccessible places were hidden in the shadows of everyday public places for most non-disabled people. These once-hidden spaces now have a bright spotlight shining down on them for me. I no longer shy away from pointing out these places because I saw that most people were unaware that these places even existed. I also noticed that only after I pointed out an inaccessible feature in a structure, the people involved were more than happy to accommodate me, like the man from my town's city planning building. Today, when I am out with friends, they are always curious to know where I had to park, given the distance of some accessible parking spaces.

In my social interactions with my disability, I also discovered the intersection of disability and age. Specifically, how age-based assumptions affected treatment and social interactions from my experience with the woman at my pharmacy and her assumption that stroke was an older person's disease. I found that my younger age protected me but at the same time disrupted my age-normative activities of a career, living alone, and being social. I also discovered from my experience with my friends that I could no longer dress in ways that expressed my age. I was also frustrated at not being able to enjoy more social outings because of my extreme fatigue.

The social assumptions and social interactions I experienced from my disability illustrated that most non-disabled people were unaware of accessible spaces yet were very understanding and more than happy to make accommodations. I learned that having a stroke at a younger age meant there was a very small social network that lacked the social support I so desperately needed.

In memories of my father, I discussed struggling with accepting help. I think this bothered me because in the past I always prided myself on being independent and capable of working through problems on my own. After my stroke, this capability was gone, and I felt embarrassed in the beginning. Luckily, through time, I regained more independence and freedom, which entailed more confidence by becoming aware of when and where I needed help and how to ask for it. Here, I learned to accept my disability, moving from resistance to acceptance to finally realizing that "it's okay" to ask for help.

Conclusion

In my autoethnographic journey, I discovered three themes: a loss of agency, identity transformation, and the intersectional role that disability played in social assumptions and social interactions. These experiences of my loss of agency illustrated that I could no longer approach my life as I had in my pre-stroke self. I needed to create a new set of skills, such as a process of finding balance and the system my mother created out in public. My sense of self was challenged after a stroke caused me to become disabled. I had to learn how to be disabled through the language, the geography of the land, and what I could and could not do through time and a trial-and-error process. Here, I found that my past learning experiences provided a solid base which I could use as a trajectory into my new identity. Disability is a misunderstood identity category and not a universal experience. The disease of stroke performs in much the same way. For example, my experience with a stroke was mine alone because of the area of my brain affected, giving me a unique disability. I was thrown into a new world of disability where I learned to adapt to what could not be fixed and inform those who had misconceptions when I was ready and on my terms. Here, I developed a mindset that was flexible and could respond to unexpected circumstances. I also learned how to understand my strengths, weaknesses, values, and what I could enjoy. I also needed to take small steps each day and focus on progress.

I went to bed eleven years ago non-disabled, but when I woke up, my body and my world as I knew it had changed. I entered a foreign and unfamiliar world where I had no clue how to navigate or even to understand the language. Help me! How can I go back home? Is there a guidebook for disability?

The captions above are from the six snapshots that scan a five-year period, which represent outside conversations that allowed me to take a deep dive into my memory, providing me with the chance to share experiences that I didn't expect to ever find a use for. This journey has made me realize "what it was" and "what it is now" to "what it will be" by re-observing these snapshot memories and experiences with a more critical eye; I hear now what I did not hear then. Perhaps I was not ready to understand these experiences. These five dialogues allowed me to have a conversation with myself today and examine what I have learned from revisiting these memories by answering my self-interview questions: How has your life changed since your stroke? What have you learned? Are there aspects in your pre-stroke life that you took for granted? What do you want people to learn from your study?

In revisiting my memories with my stroke support group, I realized that each of us was on a separate path of healing and recovery because strokes affect people differently and uniquely, and more than likely, we were all scared of what the future held for all of us. I saw how I started this journey as an outsider but through time and experience, I became an accepted member of the stroke community. In revisiting my conversation with the woman at the pharmacy, I learned that most people relate stroke to an older person's disease. I applied Morris's (2011) study to supplement this experience to better understand that more than half of young survivors perceived themselves to have enduring physical and cognitive disabilities and were dissatisfied with life after stroke, and many experienced problems caused by paralysis due to fatigue and the "invisibility" of disabilities, which predisposed colleagues, family, or friends to discount, ignore, or deny the "authenticity" of the survivor's limitations. A limitation I, too, have experienced with a family member reacting to my consistent fatigue by saying "you are always tired," which left me sad and frustrated at the time.

The psychological effects of stroke and the evidence for their occurrence were reduced quality of life, associated with dependence, depression, being single, fatigue, and being unemployed. The experience at my town's city planning office showed that if you are not disabled, you will not experience or understand the implications of a needed accommodation because it does not affect your daily reality. There was an example of ability privilege in entering a building and climbing stairs without thinking about it. The experience with my friends revealed a different example of ability privilege: being able to wear anything you want to. I also noticed that my ideal sense of beauty was impacted by a preferred non-disabled view.

Experiencing a stroke that caused a disability moved me into a new identity category. Returning to the past, I remembered how society was ill-equipped as well, because participating in a world not made for disabilities is both exhausting and frustrating. For example, observing accessible parking was available, but it was often provided at a distance (perhaps as an afterthought); accessible restrooms—yes, available, but only one available.

During this autoethnographic experience, I first followed their chronological order, the only thread I initially perceived tying them together. But then I realized that a sociological understanding of people's knowledge of stroke contradicted my own ideas of living and learning with a disability. Once I had finished crafting and carefully examining the snapshots, I saw a link between personal to theories that centered attention on relationships between myself and others. I discovered that relationships between the body and self are fused to the personal and the societal over time, which extended sociological understanding of living and learning with a disability. I also saw that autoethnography is a way of mobilizing the theoretical intent of critical disability theory, which holds real significance as a method interested in interrogating constructions of self and enabling emancipatory pedagogical practices. Essential in autoethnography, as autoethnographers seek to show "two selves “the "before self" and the "after self" that emerges after a transformational experience (Bochner, 2000).

More widely, perhaps it also has potential for the engagement of a larger social dynamic outside the professional parameters of education alone. As a necessarily social practice, education is intimately connected with the concerns of the social context within which it functions. On this basis, autoethnography as a method for engaging self, identity markers, and critical formations of each of these categories finds application in the excavation of the material realities of the social contexts in which it was deployed. It does so by providing moments from one's own narrative of self that focuses upon relationships with past, present, and future selves. My snapshots have yielded several themes or labels that capture the essence of the relationship between myself and other people in the scenes portrayed that I have come to understand and later to embrace. On one hand, autoethnography can recognize that different kinds of people possess different assumptions about the world—a multitude of ways of speaking, writing, valuing, and believing—and that conventional ways of doing and thinking about research were narrow, limiting, and parochial. These differences can stem from sexual orientation, age, ability, class and education, or religion. Autoethnography, on the other hand, can expand and open a wider lens into the world, eschewing rigid definitions of what constitutes meaningful and useful research; this approach also helps one understand how the kinds of people we claim, or are perceived to be, influence interpretations of what we study, how we study it, and what we say about our topic.

This journey has made me realize that strokes affect people differently, and I was not able to find similar post-stroke experiences as a result. However, I did find similarity in Sparkes's (1996) narration of himself as he explained and demonstrated in his daily journals his hatred and anger towards his fatal flaw, which was a lower back problem that had taken his love and joy of sports away from him and how he was lost without his athletic body and his sole identity of male and masculinity of self was also lost. He acknowledged that he built his life around his fatal flaw by working out and weight training to hide his flaw, "to build the shell of muscles to protect him from who he was and who he wasn't." This became an embodied cycle of events that increasingly shaped his life. As a juxtaposition to my own feminine insecurities, I found in returning to my friend's snapshots.

Relationships between culture and knowledge production are interconnected, and one influences/informs the other, and the knowledge I have is influenced by my life experiences and the values gained by them. I have found that each of these categories supports an application in the way they are understood as the material realities of the social contexts in which they are applied. For example, my racial identity has afforded me the privilege to question the ability-disability binary, which informed my other identities of class and gender that intersected with my disability. These intersections did so by providing moments from my narrative of self that focuses upon relationships between the past, present, and future self.

In crafting and reliving my memories considering several readings and reflections, I created and recreated my sense of identity (Murdock, 2003, p. 11) as a stroke survivor and a learner—a sense of identity that has included reaching a renewed understanding of the inherently relational aspects of living and learning.

Chapter Five: Discussion

In this final chapter, I examine how my experiences discussed in Chapter Four, combined with the literature in Chapter Two, offer a deeper understanding of the disability experience as I step back to view the broader picture. My narratives reveal how everyday interactions elucidate personal experiences about stroke, disability, adaptation, social understanding, and societal attitudes. Through these stories, I identified three key themes that shaped my understanding of disability: the loss of agency, identity transformation, and the intersectional role disability plays in social assumptions and interactions.

Loss of Agency and Adaptation

In my loss of agency, I discovered a need to rethink and approach how I once viewed my independence and dependence. I discovered that by relying on others, this also helped me to become more independent. I realized that I could no longer approach my life as I had in my pre-stroke self. I needed to create a new set of skills, such as developing a mindset that was flexible and could respond to unexpected circumstances. I also needed to understand my strengths, weaknesses, values, and what I could enjoy. I needed to take small steps each day and focus on my progress. In my journey, I learned what works and what does not work on a trial-and-error basis. For example, if I needed to go to a new place, I had to look online or call ahead to see if this facility was accessible for me, which was now a part of my daily decision-making process to maintain a sense of my autonomy. Today, I know where the best and closest accessible parking spaces are. I have discovered that I needed to be proactive and create a set of skills to eradicate a loss of agency in my new world of disability.

Identity Transformation

Disability manifests in different ways, shaped by a person's culture, experiences, and relationship to their disability. While common patterns exist, each person's experience is unique and influenced by their specific identities and circumstances. In my journey, I've found that disability creates a complex, layered experience through its interaction with other identities. The challenges and privileges associated with disability can be amplified or diminished by factors like race, gender, socioeconomic status, and sexual orientation—leading to distinct forms of discrimination and marginalization. A person's disability isn't experienced in isolation; rather, it intersects with other aspects of their identity to shape their lived experience. When different identities overlap, as with a disabled person of color, they face unique challenges stemming from both racism and ableism. These intersecting identities can intensify marginalization—for instance, a disabled person from a low-income background often encounters additional barriers to employment and education. Research supports this: Horner et al.'s (2003) study found that people of color with disabilities face discrimination based on both race and disability, resulting in disparities in healthcare access and employment opportunities. Similarly, Twardzik et al.'s (2019) study showed that individuals with disabilities from lower socioeconomic backgrounds often have limited access to assistive technology and necessary accommodations due to financial constraints.

Accessibility issues can be compounded by other identity factors, particularly gender. A disabled woman, for instance, may encounter more barriers in healthcare access than a disabled man due to gender-based biases in the medical system. Disabled women also face unique challenges because of their social roles. Kvigne's (2004) study revealed that post-stroke women struggled to maintain their sense of self, which was closely tied to their roles as mothers, wives, grandmothers, and homemakers. While pursuing these roles, they battled depression and fatigue, leading to frustration. One participant, Sofia, a 37-year-old mother of three—mirrored my own post-stroke experience. Paralyzed on one side, she struggled to resume her pre-stroke life due to depression and fatigue. The women in this study, I observed, had to push through these challenges to preserve their identity. This helped me realize I would never fully regain my pre-stroke abilities. To maintain my sense of self, I developed new approaches to daily activities, such as spacing out and limiting tasks to manage fatigue and frustration.

Rexrode et al.'s (2022) review highlighted how biological sex factors contribute to younger women's stroke risk, particularly through female-specific factors like oral contraceptive use. I recall dismissing warnings about combining contraceptives with tobacco, caught up in my youthful sense of invincibility. Now, post-stroke, I'm keenly aware of stroke-related health risks. The review found that women experience poorer functional recovery and lower quality of life after stroke than men (p. 513). The social context differs too—women typically experience strokes 4 to 6 years later than men, making them more likely to be widowed, unmarried, or living alone. This often results in greater disability in daily activities. My situation paralleled these findings: single, living alone, and self-sufficient when my stroke occurred, which intensified my post-stroke challenges. Rexrode et al. (2022) also noted that "Women remained significantly more likely to have higher prevalence, incidence, or increased number of symptoms of depression than men after multivariable adjustment for factors such as age, stroke severity, and activity limitation" (p. 522).

Tarihoran et al.'s (2023) study of younger stroke survivors revealed three main impact areas: stroke onset and early experiences, physical and psychosocial effects, and changes to roles and careers. Participants described their stroke as "a moment that suddenly changed their entire, previously busy, independent, and productive lives" (p. 3). These impacts were comprehensive, affecting every aspect of their lives. Physical limitations, particularly affecting motor function, movement, and balance, emerged as one of the most significant daily challenges. For young women, these physical and psychological impacts severely affected their roles and careers. My stroke similarly transformed my once-busy, independent life, with my solitary living situation making recovery especially challenging. I discovered that my age and life stage were the most profoundly impacted areas.

My stroke-induced disability forced me to reimagine my sense of self. Through language, physical space navigation, and trial and error, I learned to adapt to disability. I quickly understood that I couldn't approach my post-stroke life with pre-stroke expectations. My public interactions helped me develop meaningful strategies to navigate challenges and adapt to disability. I've actively shaped my understanding of disability while gaining agency. My environment and social interactions have profoundly influenced how I embody and express my identity. By actively engaging my body in this learning process, I've seen how my lived experience intertwines with physical experiences and social interactions, connecting me to broader contexts. This embodied learning has allowed me to use past experiences as foundation stones for understanding my disability. Who am I? I remain a nomad, now traversing the landscape of disability. I've woven my unique challenges and strengths into my self-perception and worldview, discovering my identity through embodied knowledge and lived experience. I've learned that both stroke and disability experiences are deeply personal, as is the journey of identity transformation.

Social Assumptions and Interactions

I have learned that most people fear being labeled as disabled because of the long histories of stigmas attached. Why would anyone want to be treated differently and presumed to be helpless and unable to make decisions? I would strongly answer "no one" until it happened to me in the rehabilitation hospital, where I was treated differently and made to feel that my future goals were unattainable.

Eleven years have passed since my stroke and two encounters at the rehabilitation hospital. Though I hadn't yet learned about disability studies or ableism during those experiences, I knew I was being treated differently—and I deeply disliked how that treatment made me feel. To help my understanding of my two experiences at the rehabilitation hospital, I needed to find an academic structure that would best demonstrate and provide understanding to my two experiences of power dynamic shift and loss of agency. Here, I applied Friedman and Owen's (2017) study where I discovered the concepts of ableism — a value system that discriminates against people with disabilities — and Othering — a behavior that excludes someone because they are different, two concepts grounded in critical disability theory. This study examined how explicit and implicit attitudes play an integral role in people's "true" attitudes. However, explicit (conscious) attitudes may not reveal all attitudes because individuals might be unaware of their prejudiced views, showing negative perceptions of disability may transcend political lines (Friedman, 2016). Harmful disability portrayals, representations, and stereotypes are so pervasive that they are often accepted without question and not recognized as negative. Consequently, most people are likely unaware of the problematic nature of their understanding of disability.

Only now do I have the language or labels that described my feelings from these experiences. Here, I learned that my new disability equated to a shift in the ways people saw me.

In Friedman and Owen's (2017) study, I learned that ableism is a social process of discrimination and bias, and oftentimes people may have implicit and explicit attitudes towards disability. I was the same person; the only difference was now I was disabled.

My two experiences at the rehabilitation hospital displayed implicit attitudes towards my disability. I know that I too had an unconscious bias about disability before I was disabled, which was conditioned and taught through society's view of people with disabilities. I have learned from these two experiences that they each placed their own ableist attitudes onto me.

Through my social interactions, I discovered how disability and age intersect, particularly in how age-based assumptions affected my treatment. This became clear in my experience with a pharmacy worker who assumed stroke was exclusively an older person's disease. Morris's (2011) study helped me understand this experience better, showing that more than half of young stroke survivors face lasting physical and cognitive disabilities and feel dissatisfied with life after stroke. Many struggle with paralysis, fatigue, and the "invisibility" of their disabilities—leading colleagues, family, and friends to discount or deny the authenticity of their limitations. I experienced this firsthand when a family member dismissed my persistent fatigue by saying "you are always tired," leaving me feeling sad and frustrated. Similarly, at the pharmacy, once the worker learned my disability wasn't from a skiing accident, her curiosity transformed into pity—a reaction that echoed the experiences described in both Scott's (2015) and Lournes's (2021) autoethnographic studies on disability.

While my young age offered some protection, it also disrupted normal life activities like pursuing a career, living independently, and maintaining a social life. Through interactions with friends, I realized I could no longer dress in age-appropriate ways. The extreme fatigue prevented me from participating in many social activities I once enjoyed.

To help manage my fatigue, I learned to space out my public errands. Over time, I became more confident in pointing out inaccessible places—I realized most people were simply unaware these barriers existed. When I brought attention to accessibility issues in buildings, people were usually eager to help, like the official at my town's city planning office. Through this process, I discovered that while addressing my own accessibility needs, I was also educating my community about disability spaces that remain invisible to non-disabled people. Wolbring's (2014) study taught me about ability privilege—the unearned advantages that physically and mentally able people experience in society without realizing it. This privilege stems from society's assumption that everyone functions at the same ability level, creating barriers for people with disabilities. It means being able to access public spaces, transportation, and daily activities without considering accessibility features. I never knew that being non-disabled was a privilege until it was taken away.

Theoretical Implications

My study contributes to Disability Studies and Curriculum Studies through my embodied learning experiences, which deepen subject-specific knowledge and enhance research capabilities. This work reveals diverse perspectives by engaging with various viewpoints and theories, broadening understanding and promoting change. Such research generates valuable insights about student learning, teaching methods, curriculum development, and educational challenges. It identifies effective teaching interventions and adds to our field's collective knowledge. When teachers access these findings through publications and professional development, they can implement evidence-based practices that improve student learning. My personal journey began when I noticed shifts in my treatment at the rehabilitation hospital—particularly how attitudes changed once people learned my disability was permanent.

Disability Studies

Both disability studies and critical disability studies examine the meaning, nature, and consequences of disability across various disciplines. Disability Studies generally examines disability as a social and cultural construct, while critical disability studies takes a more critical and political approach, analyzing how systems of power, including ableism, affect people with disabilities. Both view disability as a social construct, not solely an individual impairment.

Critical Disability Studies explores how disability as a set of meanings influences, and even structures, social relationships both through and beyond personal experiences of disability. According to Friedman and Owen's (2017) study, one important example of this move is the development of the concept of ableism, or the compulsory preference for non-disability (Campbell, 2009). Ableism, like other "isms" such as racism and sexism, describes discrimination towards a social group, in this case disabled people, but it also describes how certain ideals and attributes are valued or not valued (p. 3). For example, walking is more socially valued than moving by way of wheelchair (Hehir, 2007). Disabled people have expressed that the negative effects of ableism have been socially and psychologically damaging to them. Friedman and Owen (2017) also explored how both explicit and implicit attitudes can play an integral role in people's "true" attitudes. However, explicit (conscious) attitudes may not reveal all attitudes because individuals might be unaware of their prejudiced views.

Critical Disability Studies starts with disability but never ends with it: disability is the space from which to think through a host of political, theoretical, and practical issues that are relevant to all (Goodley, p. 157). Critical Disability Studies, then, captures some of the sophisticated ways in which bodies, knowledge, and technology merge. Critical Disability Studies have developed theories that are in concert with contemporary lives, the complexities of alienation, and rich hopes of resistance. Hence, Critical Disability Studies and Disability Studies are both fields of scholarship that concern themselves with the representation of disability across social, cultural, historical, and political contexts. In many ways, similarities might be drawn between the project of Disability Studies and other social theories of human difference, such as gender studies or race/ethnicity studies. In this way, Critical Disability Studies is an emancipatory and developing discourse (Goodley, Liddiard, & Runswick-Cole, 2018: 206; Meekosha & Shuttleworth, 2009: 48). Thinkers use the method to describe the sociopolitical constructions of disability and track the impacts of these constructions on oppressed persons, including but not limited to those to whom the concept "disability" attaches. Erevelles (2014) finds that not "everyone is disabled" but prefer historically embedded materialist accounts of disability at intersections among multiple categories of analysis, including "race, class, gender, nation, and sexual identity" (p. 219). Moreover, it is through exploring the heritage and construction of the disability identity, and when that identity is in flux with multiple categories, that we understand how they are related to the very nature of human embodiment. The disability identity needs increased knowledge in the awareness of its different kinds, values, and realities.

Embodiment is central to disability studies in that the focus on disability makes it easier to understand that embodiment and social location are one and the same. Disability creates theories of embodiment more complex than the ideology of ability allows, and these many embodiments are each crucial to the understanding of humanity and its variations, whether physical, mental, social, or historical (Siebers, 2008). According to Siebers, a theory of complex embodiment understands disability as an epistemology that rejects the temptation to value the body as anything other than what it was and that embraces what the body has become and will become relative to the demands on it, whether environmental, representational, or corporeal. The ultimate purpose of complex embodiment theory is to give people with disabilities greater knowledge and control over their bodies in situations where increased knowledge and control are possible. Siebers (2008) believed disability is experienced through a combination of both internal bodily limitations and external social barriers; essentially, it acknowledges that disability is both "in the body" and "in the world" (p. 290). There is also an interaction between a person's physical body, their social environment, and how society perceives their impairments through three phases: 1) individual experience based on personal factors, social context, and how a person interacts with their environment; 2) the rejection of the "normal" body by challenging the idea of a "normal" body, arguing that all bodies are unique and can experience disability in different ways; 3) finally, embracing the body as it is by accepting their bodies as they are, including their impairments, and navigating the challenges and possibilities that come with them. Siebers (2008) illustrates that "knowledge is socially constructed," furthering that "identities are also socially constructed." The disability identity involves the "lived experience of a physically different body," acknowledging both the social and physical aspects of disability within a single framework; essentially, it suggests that disability is "a complex interplay between the body itself and the social environment it exists in" (cited in Siebers, 2008, p. 295).

Because the disability experience is unique and not a universal experience, and there are hundreds of different disabilities — some are congenital, most come later in life, or in my case, a stroke — by using my personal disability experiences as the primary data source and using deep self-reflection, I was able to discover the intersection between personal and societal experiences. Here, I critically analyzed the cultural phenomena through my insider perspective. I prioritized my reflexivity and presented my findings through evocative narrative writing by linking my personal experience to broader cultural contexts and other academic fields, like Curriculum Studies.

Curriculum Studies

The common thread of my bodily experience continues to weave through the field of Curriculum Studies, which uses the viewpoint within curriculum and instruction concerned with understanding curricula as an active force of the human educational experience. Education is viewed in the social and cultural context, examining how social and cultural factors influence curriculum development and student learning and provide its members with important knowledge including basic facts, job skills, and cultural norms. These experiences can take shape in forms both planned and unplanned but overall come from the lived experience of the individual, social, and cultural interpretation process. As a scholar in the field of Curriculum Studies, I looked at my material world and tried to understand how knowledge was constructed and how this way of knowing was connected to the human experience. My journey to better understand my life post-stroke started with currere before it became an autoethnographic study. This curriculum theory-informed process of narration becomes a vehicle for understanding the nature of the self. Pinar's (1975) concept of currere, or "curriculum of life," seemed to be a natural fit with the storytelling traditions of autoethnography mentioned above. Whereas currere examines an individual's perspective on a concept, autoethnography extends currere by employing the individual voice in dialogue. Currere provides a strategy for students of the curriculum to study the relations between academic knowledge and life history in the interests of self-understanding and social reconstruction, which can act as self-praxis in that we are socially constructed through the mediation of powerful discourses and their artifacts. Currere allowed me to turn inward and examine my experiences, towards a deeper understanding of myself and my outer world.

In curriculum studies, a question that is often asked is “Whose knowledge has been deemed most worth?” which can also be interpreted as “Whose stories get to be told?” When considering the (in)visibility of people with disabilities and their stories. We must first examine and try to understand the barriers that many people with disabilities might face like attitudinal, physical, and social barriers. These barriers can significantly impact a person's ability to participate fully in society. Attitudinal barriers are formed from negative perceptions, stereotypes, and biases held by others, leading to discrimination and exclusion. Physical barriers are the environmental obstacles, such as inaccessible buildings, public transportation, or technology, that restrict mobility and access. Social barriers hold the broader social and cultural factors that can hinder inclusion, such as lack of awareness, stigma, and inadequate support systems. As I have learned and expressed previously that the disability identity needs greater knowledge and control over their bodies in situations where increased knowledge and control are possible. Siebers (2008) believed disability is experienced through a combination of both internal bodily limitations and external social barriers; essentially, it acknowledges that disability is both "in the body" and "in the world" (p. 290). I believe that is crucial to examine the barriers that many people with disabilities face, including my own barriers that I have experienced and share our stories in creating a platform to better see and understand the disability experience so that we can all work together to raise awareness of the barriers that still exist. I believe by writing and sharing our stories we give valuable insights into our lives and help other people to better understand the hidden world of disability. Stories provide platforms to share and give voice to rich experiences of the often overlooked disability population. These stories are significant in that they provide an experience for others to compare to and might even provoke a courage and a confidence to share their stories. For me, this autoethnography allowed a deep introspection, which accessed thoughts, feelings, and bodily sensations. It blended vivid, emotive memories with broader social and cultural aspects, transforming experience into a rich, contextual story of my post-stroke experience.

Exploring a particular person in a particular place and time encompasses all that the person has been and undergone in the past and in the past of the tradition which has helped to shape the person — or in my case, myself. This can be a description of a person's history, but it can also be a meaning-giving account, an interpretation of one's history that provides a way of understanding experiential knowledge. Knowledge can be educative, whether it occurs in school or not and whether it is private, social, or academically formal, because this is where we gain our knowledge and our sense of our world as we see it. These experiences constitute an altered way of viewing events, leading to new insights and to new ways of doing things, and offer an interpretive reconstruction designed to reveal what is meaningful in a person's history for purposes of understanding actions.

Autoethnographies and Disability

Autoethnography's focus on the interconnectedness of inner and outer realities, with personal experience at its core, makes it particularly effective for communicating disabled embodiment (Adams, Holman Jones, and Ellis 2015; Richards 2012). It creates a space to untangle the complex relationships between a disabled body and a world not designed for it, revealing experiences of the physical body, the external world, and the fit—or misfit—between them. As Marks (1999) notes, it is a method that "recognizes the importance of examining the interrelationship between embodied subjects and complex social and psychic relationships" (ix).

These approaches give disabled authors tools to voice nuanced narratives of their embodied experiences. Many autoethnographers write not only for others but also for themselves (Adams, Holman Jones, and Ellis 2015; Chang 2008; Maseti 2018). Autoethnography celebrates emancipation, welcoming voices that break silences and highlight the dissonance between disabled bodies and their surroundings (Gale and Wyatt 2019; Richards 2008, 2012).

Autoethnography powerfully expresses lived experiences of specific cultural phenomena (disability) because it creates a space to untangle the complex relationships between a disabled body and a world not designed for it. The practice of autoethnography presumes that reality is socially constructed, and that meaning is constructed through symbolic (language) interaction. Ellingson and Ellis (2008) express that socially constructed categories consist of social institutions, laws, regulations, and media. The ideas that are created, maintained, and changed over time—which control conditions, convert observations to numerals, and separate truth from practice—are rhetorically constructed to privilege the powerful elite and marginalize other voices in the process of knowledge production. Autoethnography troubles these socially constructed categories by showing how they play out in the world and how we incorporate them into our identities.

Incorporating the three distinct autoethnographic studies offered valuable guidance, insights, and exemplars for my own research. By examining these studies, I gained a deeper understanding of the autoethnographic methodology and its application in academic contexts. Because the individual disability experience is unique, I felt that autoethnography provided the best method to highlight my own unique disability experience. The philosophy of autoethnography is compatible with Disability Studies. Ideally, I would like to see more autoethnographic studies in disability research because it creates a space to untangle the complex relationships between a disabled body and a world not designed for it.

Through my lived embodied experience, I discovered how my environment and social interactions played a significant role in my own understanding of disability. Through physical interactions with my environment, I have experienced people's limited understanding of disability. I have learned by doing and, in return, have constructed my own ideology of disability and who I am because of it. Here, I borrow from Siebers (2008), that the disability identity involves the "lived experience of a physically different body," acknowledging that both the social and physical aspects of disability are within a single framework; essentially, it suggests that disability is "a complex interplay between the body itself and the social environment it exists in" (cited in Siebers, 2008, p. 295). My Curriculum Studies background helped me to examine how social and cultural factors influenced my learning, understanding, and important knowledge in the preferred non-disabled cultural norms. These experiences can take shape in planned and unplanned forms but overall come from the lived experience of the individual, social, and cultural interpretation process. My autoethnography powerfully expressed my lived experiences of specific cultural phenomena and societal views of disability and created a space to untangle the complex relationships between a physically different body and a world not designed for it, while troubling the socially constructed categories by showing how they play out in the world and how we incorporate them into our identities.

In this process, I experienced disability through a combination of both internal bodily limitations and external social barriers. I have learned that what I cannot fix, I can adapt to with help from people in my community. As a result, people were more than happy to accommodate my needs. Here, I was my own advocate and helped educate people about inaccessible places. I have also learned that I cannot approach my new post-stroke life in the same way as my pre-stroke self. Essentially, it acknowledges that my disability is both in the body and in the world.

Practical Implications

Eleven years ago, I entered the foreign world of disability, knowing nothing of its language or culture. My parents and I were completely unprepared for this life-changing journey. I had to build my understanding through lived experience, learning what worked and what didn't. Over time, I developed skills to manage situations that once left me frustrated and fatigued. I discovered that my age was the most challenging obstacle—I was struck by a stroke at a point in life when I was single, living independently, self-sufficient, energetic, and socially active. In an instant, everything changed. At 39, I had already experienced much of what the world offered, yet I was too young to be living life at a slower pace. Now I walk with a cane, forcing me to slow down. I've come to accept this new rhythm of life—**it's slower, not over, as I often remind myself.**

My experiences at the rehabilitation hospital stroke support group demonstrated that my young age was a key factor, as I was the youngest there and needed a hobby to fill my free time. The healthcare providers at the rehabilitation hospital treated me differently now that I was disabled by taking away my freedom of choice in medication, as well as my ability to continue my future academic endeavors. A better and more productive scenario would have been these healthcare providers asking me my thoughts and wishes for my future and asking, "How can we help make this happen for you?" When I was asked and heard, I had control over my life again. I would recommend that healthcare providers first ask patients what they want for their futures and work to help them achieve their goals. Just because a person is disabled does not equate to an inability to think for themselves; a simple dialogue would more than suffice.

To better help me understand my changed treatment at the rehabilitation hospital, I looked to Friedman and Owen's (2017) study and VanPuymbrouck et al.'s (2020) study that both explored explicit and implicit attitudes towards disability. Both reported that while participants claimed not to be biased against people with disabilities, implicitly, the overwhelming majority were biased and preferred non-disabled people. However, a study by Lezzoni et al. (2021) indicated that approximately half of physicians "strongly agreed" that they would welcome a patient with disabilities into their practice. Additionally, approximately one-fifth of physicians surveyed "strongly agree" that the healthcare system treats patients with disabilities unfairly. The findings of this study suggested that physicians in the US hold bias or stigma toward patients with disabilities. Physician self-efficacy can be enhanced through confidence in providing culturally competent care to patients with disabilities. This can be achieved through attending trainings and simulations with patients with disabilities. They suggest that "All levels of medical education should include more training about disability, including disability cultural competence and etiquette" (p. 305). Training provides greater empathy about patients' daily lives. Learning this, I wondered if my experience at the rehabilitation hospital was a form of ableism or was it that they both lacked empathy? What a relief if my changed treatment could be solved through training programs in healthcare providers. Empathy offers numerous benefits, including fostering stronger relationships, improving communication, boosting creativity, and enhancing emotional well-being, both personally and professionally. It is important to build positive relationships because when patients with disabilities are made to feel in an inferior role in a relationship, they are less likely to advocate for themselves, ask questions, and feel like an equal partner in their care.

A stroke is not a one-size-fits-all experience, nor is the degree of disability it brings, which makes disability services impossible to predict and prepare for. However, I would suggest age-normative physical and occupational therapies to better prepare the individual for whatever they plan to accomplish next in their post-stroke life. Disabled young people are a unique group because we are all at different age-normative life activities such as education, career, and family. However, disabled young people have lower levels of mobility and participation in recreational activities because of physical, social, and cultural barriers compared to their peers without disabilities. Participation in community life is vital for health and wellbeing, promoting a sense of belonging, networks of social support, and opportunities for physical activity. Social participation is not a one-size-fits-most approach. It varies widely according to the type of disability and age/life stage of the individual. Carroll et al.'s (2018) study found that having a "toolbox" of different approaches aids in social participation for the individual; however, the details are best negotiated in vivo or embodied on a case-by-case basis. I, too, constructed tools that I used to aid in my inclusive social participation. Essentially, young disabled people need to find their own set of tools that works for them. Young disabled people also need to find a purpose that motivates them.

For young stroke survivors, I recommend age-normative physical and occupational therapies that focus on their future goals post-stroke. Atler's (2016) study "The Experiences of Everyday Activities Post-Stroke" examined how community-dwelling stroke survivors experience daily activities and identified factors influencing these experiences during occupational therapy sessions. Atler aimed to enhance understanding of the post-stroke lived experience, focusing on describing activity-related experiences in the context of daily life. This study was notable for providing insight into stroke survivors' activity experiences within the framework of actual time use. Stroke survivors completed the Daily Experiences of Pleasure, Productivity and Restoration Profile (PPR Profile)—a time-use survey—on three separate, self-chosen days within one week. Participants subsequently completed individual, semi-structured interviews. The PPR Profile was designed to capture pleasure (sense of enjoyment), productivity (sense of accomplishment), and restoration (sense of renewal), which have been identified as human need-based experiences associated with everyday activities. The study showed that lived experiences of pleasure, productivity, and restoration were influenced by the convergence of internal and external factors. Atler concluded that stroke survivors' "lived experiences of pleasure, productivity and restoration in the context of everyday activities yielded insight into the survivors' recovery and adjustment processes and into their quality of life" (p. 781). Experiences of pleasure described by the participants were related to feelings, with the most common theme connected to feeling good. Words such as "feeling good," "enjoying," "makes me happy," and "fun" were commonly used. Some participants talked about feeling good in connection to being able to engage in activities that might previously have been difficult post-stroke (Atler, 2016, p. 784). After my stroke, I needed to find a sense of purpose. Fortunately, in my therapies, I found a sense of accomplishment as I attempted to reach my goals of attaining my independence again. Understanding stroke survivors' lived experiences can provide valuable insights to practitioners, family members, and others invested in promoting the recovery process. For young disabled people, it is important to find ways to participate in public and social activities to maintain younger lifestyles and have a sense of purpose, accomplishment, and joy.

Future Research Directions

To advance this research, I must first acknowledge its limitations. I could not find comparable post-stroke experiences among younger women to contrast with my own. While autoethnographic studies offer valuable insights into an author's lived experience within specific cultural contexts, they are inherently limited to a single perspective. Alternative methodologies—such as interviews with multiple participants—would provide diverse viewpoints. My experience reflects that of a white, middle-class female, which excludes other perspectives across race, gender, age, and sexual orientation. Additionally, my observations were confined to a small rural Texas town, rather than other environments like metropolitan cities. These demographic, cultural, and environmental factors would likely yield markedly different experiences. Looking ahead, I aim to explore disability experiences more comprehensively by conducting studies that encompass broader contexts and populations. Understanding how various demographics and cultural contexts shape the disability experience would provide deeper insights. Including diverse social identities would better illuminate the multifaceted nature of disability experiences.

Personal Reflections on the Research Process

Through my autoethnographic journey, I discovered three key themes: loss of agency, identity transformation, and the intersectional role that disability played in social assumptions and interactions. These themes were connected by my embodied learning experience. The field of Disability Studies has been instrumental in helping me understand that embodiment and social location are inseparable. As Siebers (2008) notes, both knowledge and identities are socially constructed. This understanding has helped me recognize the emergence of my "before self" and "after self" (Bochner, 2000).

My journey through disability has involved three distinct phases: first understanding my individual experience within my social context, then challenging traditional notions of the "normal" body, and finally embracing my body with its unique characteristics. This progression has led to both acceptance and pride in my accomplishments.

Autoethnography, as a methodology, reveals how socially constructed categories manifest in real-world experiences. Drawing from Ellingson and Ellis (2008), these categories - embedded in social institutions, laws, and media - often privilege certain voices while marginalizing others. My research challenges these constructs by demonstrating their real-world impact on identity formation.

As a scholar, my perspective has been uniquely shaped by experiencing both sides of accessibility issues. Before my stroke, I never noticed physical barriers in my environment. Now, I understand why the non-disabled population might overlook these challenges. This dual perspective has enriched my interpretation of how social and cultural factors influence disability experiences.

Lessons Learned

I have learned that there is a real need to provide more age-appropriate resources for young disabled people, and especially for young stroke survivors like me. It was a relief to discover that the health care workers lacked empathy instead of displaying an ableist mentality. This research has helped to foster my resilience, promote my personal growth, and expand my perspectives.

Resilience

My resilience has enabled me to build coping skills that have further promoted adaptability to make unexpected adjustments and to be flexible, which has allowed me to navigate challenges more effectively, without frustration. For example, I know my environment and what is needed when I go out into my community.

Personal Growth

My personal growth has offered opportunities for self-reflection, learning, and the development of resilience, ultimately leading to a deeper understanding of my strengths and myself and my world. These new experiences required learning new skills while refining existing ones, which in turn has contributed to my overall competence and adaptability.

Perspectives

My perspectives have been expanded by being exposed to new disability ideas, cultures, and ways of thinking, fostering empathy, and allowing me to see situations from different angles, ultimately leading to a more nuanced and comprehensive understanding of the world. In this process, I have developed empathy by gaining a greater understanding of others' feelings through listening to and learning from their experiences via stories, discussions, and observations. I have learned about disability and how others know and understand disability. This experience has broadened my understanding of disability culture through my own challenging situations and disability experiences.

My new experiences have the capability to expose situations that contradict preconceived notions about disability and what it means to be disabled. Experiences, particularly those that take us outside our comfort zones, can broaden our worldview and help us see the world as a more complex and interconnected place. Even negative experiences can be valuable learning opportunities that teach important lessons and help shape our perspective in ways that positive experiences might not. I believe that working with others on projects or tasks can expose us to different approaches and perspectives, leading to more creative and effective solutions.

The significance of my study has highlighted that society has little understanding of disability, and what is known is either misunderstood or negative. There was a real intersection of disability and age that demonstrated a need for new and better resources for young people with disabilities, because for me, my age was the hardest issue to overcome. It has been nearly thirty years since the Americans with Disabilities Act (ADA) went into law, and there are still inaccessible spaces in public places. Health care providers lack cultural etiquette or understanding of disability culture, which suggests future training in areas of empathy and building stronger health care relationships. My research is important because it shared a personal experience of how I came to understand disability by becoming disabled and learning how to navigate my physically different body. My study contributes to Disability Studies and Curriculum Studies through my embodied learning experiences, which deepen subject-specific knowledge and enhance research capabilities. This work reveals diverse perspectives by engaging with various viewpoints and theories, broadening understanding and promoting change, acknowledging that both the social and physical aspects of disability exist within a single framework. I have found and stated elsewhere in this study that there is a need and demand for more research on the experiences of younger people with disabilities and preferably younger stroke survivors' experiences.

I remember years ago, when I was in the thick of first experiencing disability, feeling overwhelmed, frustrated, and helpless. Now, when I look back, I see how far I have come and that I did get through it and became a stronger and wiser person because of it. I am proud of myself and I know that both my parents are proud of me, too. Looking forward, I hope my lived experience will encourage others with disabilities to share their stories. There remains a critical need for research that specifically addresses the experiences and needs of young stroke survivors.

What a Long Strange Trip It’s Been

My past travel experiences have profoundly shaped the person I am today by giving me the benefits of **diversity and empathy, adaptability and resilience, problem-solving, communication skills, open-mindedness, and** spontaneity.

Experiencing different cultures firsthand broadens your perspective and fosters empathy and understanding for people from various backgrounds. Navigating unfamiliar situations and cultures requires adaptability and resilience, which are valuable skills for life. Unexpected challenges and situations during travel force you to think on your feet and develop problem-solving skills. Learning to communicate with people from different backgrounds enhances your communication skills and helps you become more open-minded, flexible, and able to appreciate different perspectives. Travel encourages spontaneity and a willingness to embrace the unexpected, which can lead to exciting and memorable experiences. These experiences have laid the foundation for my abrupt introduction into the landscape of disability. My first few encounters were at the rehabilitation hospital where I first faced different treatments, and then upon meeting other stroke survivors, where I saw firsthand that strokes impacted people differently with different disabilities. My stroke-induced disability forced me to reimagine my sense of self. Through language, physical space navigation, and trial and error, I learned to adapt to disability. I quickly understood that I couldn't approach my post-stroke life with pre-stroke expectations. My public interactions helped me develop meaningful strategies to navigate challenges and adapt to disability. I've actively shaped my understanding of disability while gaining agency. My environment and social interactions have profoundly influenced how I embody and express my identity. By actively engaging my body in this learning process, I've seen how my lived experience intertwines with physical experiences and social interactions, connecting me to broader contexts.

My autoethnographic research allowed me to understand unique ways of thinking and feeling that helped me make sense of my interactions with others, particularly in the presence of power relations. A benefit of using the autoethnographic method is that it introduces unique ways of thinking and feeling that help make sense of oneself and one's interactions with others, particularly in the presence of power relations and social activities. This research has given me the insider perspective gained through being immersed in a cultural context as a source of privileged understanding (Ellis, 2004). Overall, I have seen myself transition from an outsider to an insider in disability studies and Curriculum Studies by raising my consciousness of disability space, language, and culture, which in turn has promoted my growth and a deeper understanding.

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Postscript

A Curriculum of Recovery

In this section, I discuss my thoughts of recovery and living with disability as a curriculum. Using the philosophy that the curriculum is defined as a lived experience, as a tool to prepare students for life, as a system, as a plan for a specific subject area, as a content, as an activity or opportunity to learn from, and as a belief system. For the purposes of this study, I viewed curriculum as a composition of unplanned experiences, and as a series of experiences of opportunities. I examine the difference of a stroke as a medical diagnosis and as a social disability diagnosis. My recovery and living with disability curriculum had two different paths- the “official” and the “lived” recovery curriculum. At the time of my stroke diagnosis, I had no idea what that even meant, I began by asking questions to better understand the concept of a stroke and later on the consequences of the disability it had created. I learned by doing out in my community through a trial and error process. My ability to navigate were strengthened by my past experiences once I understood what knowledge I needed to acquire to reach my goals. Bottom line, I needed to ask for help or an accommodation, but did not know how or that I might need it in my future. This section ends with a personalized stroke curriculum to help other young stroke survivors.

From a curriculum perspective my experience was unique because it was an individual experience of the type of stroke I had and the severity of the disability it created and how I came to understand and use my daily living and social participation insights towards my recovery. I learned that I needed more information and understanding towards my stroke and disability because the knowledge needed was not available in my toolbox. I had to create and develop my own curriculum. This discovery was important because it presented an absence in important disability knowledge regarding the principles and practices of my curriculum development, implementation and approaches needed. By thinking of my recovery and living with disability as a curriculum helped me to better understand how age factored into my curriculum all in while, I was building and learning my identity. In my curriculum I saw the differences between the medical diagnosis of stroke and the social diagnosis of disability where they separated and how I saw clarity in understanding and interpreting my recovery.

Age

From a curriculum perspective, age, as a belief system, gives a unique opportunity to learn from. Because age or ageism is a social construct that creates stereotypes, prejudices and discrimination. It means different things in different cultures and affects how individuals are perceived and treated based on their age. Because the meanings, expectations, and roles associated with different age groups are not universal but are shaped by societal norms, values, and cultural beliefs. Society assigns specific roles and expectations to different age groups. Expectations can influence how individuals are treated and perceived by others, potentially impacting their life opportunities and experiences. It is important to learn about ageism, its impact, and how it manifests in society. For example, expectations and stereotypes about what people of certain ages should do or be like are part of these social constructs, impacting everything from career paths to social interactions. Ageism, like ablism can operate both consciously (explicitly) and unconsciously (implicitly), and it involves bias behaviors. Because stroke is associated in being attached to older people, only now medical fields are realizing that strokes are now on the rise for younger people. Age intersects with other social categories like gender, race, and class, further shaping an individual’s life experiences. My young stroke age impacted my social interactions, my self-concept and my behavior until I learned how to adapt them to work for me. Stroke rehabilitation needs to adapt better programs geared towards younger people's needs. Age should automatically be an individualized part of the stroke rehabilitation recovery process. I saw and experienced firsthand the difficulties in participating in social activities, in which if you don't have the knowledge or the support could lead to low social participation and isolation. The concept of learner-centered is key in my curriculum because this focuses on the age appropriate needs, interests, and experiences of what is needed towards my recovery. For example, each area in recovery should focus on my future goals and plans; the skills and strategies needed for my continuing academic endeavors.

Stroke: a Medical and Social Diagnosis

As a medical diagnosis a stroke first needs to be identified, then the type of stroke determined, assessment of the damages and finally the treatment strategies on to the rehabilitation. The medical diagnosis focuses on identifying the cause and type of stroke, while the social diagnosis considers the long-term consequences on daily living, relationships, and overall well-being. Socially, it impacts a person's ability to live independently, their relationships, and their career, which may require additional support and rehabilitation. As a social diagnosis, depending on the type of a stroke and the severity of a stroke the focus is on the disability and its impact on daily living, social interactions and partipation.

At the time of my stroke diagnosis, I had no previous knowledge or understanding of what this disease was. I do remember being told that I had a stroke from a dissection of my right carotid artery with a left side paralysis as a consequence. Once at the rehabilitation hospital I rapidly started therapy to assess the damage and to create a future rehabilitation plan that consisted of physical, occupational and speech therapy. I learned from my speech therapist that my disability would prevent me from furthering my academic endeavors. But, yet here I stand. I learned from this negative interaction that **most things are adaptable**. At this rehabilitation hospital my “official” curriculum began where I learned about the stroke diagnosis by questioning and listening to the people in charge of my care at the rehabilitation hospital to later observing other stroke survivors’ behaviors and listening to their stories from a stroke survivor’s support group. When I returned to the rehabilitation hospital for a stroke survivor’s support group I saw firsthand the other stroke survivors’ consequences from the type and location of their stroke. I saw early on that my young age might present a problem. As for my social diagnosis, I first learned how to maneuver in a wheelchair, which meant that I would not walk again and in my mind was not an option. For the six months at the rehabilitation hospital, we built up my physical strength and worked on transitioning from the wheelchair to other places like the shower chair and toilet with the future expectations of reaching independence and eventually leaving the hospital.

My official curriculum began at the rehabilitation hospital where I first learned about the stroke diagnosis from the to the people in charge of my care. At the rehabilitation hospital I learned that my disability would prevent me from pursuing my future academic endeavors as well as the way I used to traverse and participate in public.

After the rehabilitation hospital, I began my outpatient therapy where in my physical therapy I learned how to transition out of my wheelchair into an ankle-foot-orthosis (AFO) walking brace. In my occupational therapy I learned how to use adaptive equipment towards independent living, which eventually resulted in moving out of my parent’s house into my own house and driving my car again. Looking back to these memories I saw that my curriculum of recovery consisted of two curriculum theories 1. learner-centered, which consisted of my needs, experiences and interest and 2. society- centered learning, which helped me in shaping social values and promoting social change. The paralysis consequence from my stroke never limited my recovery or my goals towards my independence. We focused on my abilities and how I could adapt to certain difficulties. Not having other young stroke survivors to compare to enabled me to find other strengths to rely on. For me, my stroke diagnosis and my social diagnosis separated when I understood the stroke diagnosis and began to encounter my daily living. Because learning on my own made my experiences more meaningful and personal, which allowed me to cultivate my identity around my needs, beliefs, values and strengths that were not contingent on my stroke diagnosis. I never felt limited on my lack of abilities because my support system of my parents, friends and therapists only focused on my abilities. Once ready to explore my community my mother and I set out to run errands in my car. We started out small by only going to the grocery store. In the beginning, my mother was only there as my support until I figured out the accessibilities in my community. However, when there was an obstacle she created the strategy of the use of her body to aid in my needs. Eventually, leading to breaking down the barriers in my community, while educating on the importance of inclusive spaces.

My lived curriculum began during my months of outpatient therapy where I learned to rely on my strengths and how to use adapted equipment to better support my daily activities of bathing, cooking and driving. I learned where the accessible and inaccessible places were in my community. My knowledge learned was by discovering how and what types of questions to ask for and what I needed to know for my own future goals. My greatest aspects of my understanding was accomplished by a learn by doing approach. Ultimately, I had to live it, to learn it to understand it. A year later, when I began my PhD studies, I expanded my knowledge on stroke through other studies that explored factors of gender, age, race and socio economics. When I started researching for this study on my changed treatment of being disabled in this rehabilitation hospital I found a long stigmatized treatment towards people with disabilities with both implicit and explicit attitudes favoring the non-disabled population. I also found that I, too, had an attitude that favored the non-disabled for my dislike of wheelchair use for myself.

My official curriculum at the rehabilitation hospital left me with a negative post-stroke experience where I felt vulnerable. While my lived curriculum was positive because it provided hope through personal strategies that relied on my abilities where I felt in control. My lived experiences were deeply personal and shaped by my needs, beliefs, and values. Which situated my recovery within a broader social, cultural, and historical context, influencing how I perceived and interpreted events.

When I was in the thick of my post-stroke experiences learning to navigate my body in both familiar and unfamiliar places I remembered feeling hopeless, angry, and frustrated. After returning and capturing the essence of the interactions, conversations I saw how far I had come in the eleven years since my stroke. For my autoethnographic snapshots, I documented my observations and interactions that were relevant to my experiences, which included details about the environment, conversations, and my own reactions by first writing the narrative with dialogues within each snapshot memory, then provided an extended and detailed context to memory. I bolded a phrase or quote that stood out and then separated the narratives. In each separated narrative, I added my biases, assumptions, while blending answers from my self-interview questions of **:** How has your life changed since your stroke? What have you learned? Are there aspects in your pre-stroke life that you took for granted? What do you want people to learn from your study? The writing process of acknowledging and sharing these experiences helped me to gain new perspectives on the once hidden world of disability. It was here in my research where I saw that most people knew little about the disability culture but were willing to listen and learn as I shared my personal story on learning about being disability by becoming disabled. Like me, most people never encountered the disability experience unless it happened to someone close or to someone they know. For instance, I remembered seeing the accessible spaces and places before my stroke but did not put any value into them, which helped me to better understand why most people were unaware of the inclusive spaces until I pointed it out to them. My experiences in this research have demonstrated that my past personal experiences have enabled me to adapt to the different contextual experiences in my environment. My past lived experiences have afforded me the privilege to have encountered such powerful and educational experiences which have allowed me to gain the skill sets in order to quickly adapt to inaccessible barriers. I also learned that before my stroke I did not value the accessible spaces that I now need. In this research process I have found my own way of understanding what works for me.

In terms of the larger contexts of my life beyond the key quotes, memories, and reflections, I identified themes that impacted the way I came to understand my disability experiences. My identity transformation, and the intersectional role that disability played in social assumptions and social interactions.

Our Stories

In curriculum studies, a question that is often asked is “Whose knowledge has been deemed most worth?” which can also be interpreted as “Whose stories get to be told?” When considering the (in)visibility of people with disabilities and their stories. We must first examine and try to understand the barriers that many people with disabilities might face like attitudinal, physical, and social barriers. These barriers can significantly impact a person's ability to participate fully in society. Attitudinal barriers are formed from negative perceptions, stereotypes, and biases held by others, leading to discrimination and exclusion. Physical barriers are the environmental obstacles, such as inaccessible buildings, public transportation, or technology, that restrict mobility and access. Social barriers hold the broader social and cultural factors that can hinder inclusion, such as lack of awareness, stigma, and inadequate support systems. As I have learned and expressed previously that the disability identity needs greater knowledge and control over their bodies in situations where increased knowledge and control are possible. Siebers (2013) believed disability is experienced through a combination of both internal bodily limitations and external social barriers; essentially, it acknowledges that disability is both "in the body" and "in the world" (p. 290). I believe that is crucial to examine the barriers that many people with disabilities face, including my own barriers that I have experienced and share our stories in creating a platform to better see and understand the disability experience so that we can all work together to raise awareness of the barriers that still exist.

Shakespeare (1996) illustrates that a particularly useful metaphor for understanding the self and the disability experience is the concept of identity as narrative. This focuses on the stories we tell about ourselves and our lives, constructing accounts that encompass plot, causality, and conflict. Because the narratives we create about our lives include our past experiences, values, and aspirations, shape how we perceive ourselves and how we interact with the world. **Narratives** suggests that self- identity is not just a static label or a reflection of external factors, but rather a dynamic process of storytelling and interpretation.

Giddens (1991) summarizes this approach to self-identity: "Self-identity is not a distinctive trait, or even a collection of traits possessed by the individual. It is the self as reflexively understood by the person in terms of her or his biography" (p.53). Identity thus connects the social and personal, involving individuals placing themselves in a collective context. Giddens (1991) further emphasizes that "A person's identity is not to be found in behavior nor—important though this is—in the reaction of others, but in the capacity to keep a particular narrative going" (p.54).

Campbell (2009) suggests that critical disability studies shift attention away from ‘the disabled’ onto “the abled.” Ableist processes create a corporeal standard, which presumes able-bondedness and inaugurates the norm and purifies the ableist ideal. When disabled people (and non-disabled people for that matter) ask ‘Who am I?’ they risk being hit with the mirror of the abled self. But, following Goodley (2017), while “disabled people undoubtedly suffer the psychologization of ableism, the individual remains a key site of everyday life, oppression and perhaps resistance for everyone” (p. 92).Although the disabled self sits uneasily with the narrow construction of the abled self in contemporary society, so too do many other members of society, who are judged against equally pernicious standards of worth associated with the fully functioning self of contemporary society. Indeed, we are all engaged in the constitution of ourselves every minute of everyday day, through our relationship with others (Goodley,2017, p. 81).

The universal construct of the self is the product of the fact that every human being is aware of his/her individuality. It is a premise that human beings are consciously aware of their own lives, and it is through reflexivity that we become aware of a consciously constructed self. Self is seen as a universal human property, something that we must all possess and a characteristic that we must all develop. Self in this context enables us to reflect on who we are, whom we choose to identify with, and what we choose to do as matters of choice, not compulsion. We can choose our identity and ignore and even reject identities fostered on us because of ascribed characteristics. We do all these by creation of narratives about the self which, provided we can sustain these narratives, work to maintain our sense of self (Murugami, 2009). Moreover, a person with a disability has the capability of constructing a self-identity not constituted in impairment but rather independent of it. Here, one can establish one's sense of self in terms of their abilities as strengths without losing a sense of self.

I believe by writing and sharing our stories we give valuable insights into our lives and help other people to better understand the hidden world of disability. Stories provide platforms to share and give voice to rich experiences of the often overlooked disability population. For me, this autoethnography allowed a deep introspection, which accessed thoughts, feelings, and bodily sensations. It blended vivid, emotive memories with broader social and cultural aspects, transforming experience into a rich, contextual story of my post-stroke experience.

In sum, by thinking of my recovery and living with disability as a curriculum helped me to better understand how my young age had specific roles and expectations, which influenced my treatment and how I was perceived by others. factored into my curriculum all in while, I was building and learning my identity. In my curriculum I saw the differences between the medical diagnosis of stroke and the social diagnosis of disability where they separated and how I saw clarity in understanding and interpreting my recovery. My lived recovery curriculum was made more personal and meaningful because it was built around my needs, values and strengths. Compared to my official recovery curriculum where I was made to believe that my disability created unattainable and inaccessible goals. A curriculum should be created around a person's needs, values and future goals with a toolbox filled with adaptable strategies and tools for a successful life ahead.

Individualized Recovery Plan

As previously mentioned, a stroke and its disability is unique to each stroke survivor. The stroke recovery plan should reflect the exclusive experience. The first three months after a stroke are crucial because the brain can rapidly heal and remember its functions through early inpatient stroke rehabilitation.

First Month

After the initial stroke medical diagnosis and stabilization, early inpatient rehabilitation should begin to access the survivor's affected areas. After the assessment a rehabilitation team, which consists of a neurologist and the therapist involved in the physical, occupational and speech aspects of the treatment meet to discuss the survivor's results and create an individualized recovery plan. This meeting is crucial in the survivor's recovery plan because the team discusses the type of stroke and the disability it created while discussing how each area in the therapy will benefit and improve the affected areas. More specifically, the team learns about the survivor's past and pre-stroke life and how their past experiences might be used to better assist in the recovery. The team makes inquiries about the future aspirations after the rehabilitation hospital and how each therapy could be used and catered around each future goal. The team and the survivor work together and build an individualized recovery plan. This individualized recovery plan is designed around the survivor's age, needs, values and past experiences. The team meeting takes place in the first week of the stroke rehabilitation hospital and continues to meet every month to check in on progress and or concerns. After each team meeting the survivor and care givers meet with a mental health counselor. Physical, occupational and speech therapies are built and work on the needs and goals of the survivor and recovery team for the first three months of inpatient rehabilitation hospital. In the second month at the rehabilitation hospital the therapies are increased in difficulty and the team, and the survivor meet for the monthly check in with a follow up meeting with the mental health counselor.

Third Month

In the third and final month at the rehabilitation hospital the therapies are increased again in difficulty and the team, and the survivor meet for the monthly check in with a follow up meeting with the mental health counselor. However, now in the final month the focus is centered on the return to home and on what to expect from the new aspect of the recovery and what will be needed. This future preparation step is important for both the survivor and his/her caregivers because the return home and moving again out in public is a new part of the recovery process.

The Return to Home

Although the physical location of home remains familiar, how the stroke survivor interacts with the home has changed dramatically. As part of the recovery process the survivor and the caregivers need to create a new system of care. For example, set times to shower, dress and eat. The home environment needs to be a calm and quiet because a change in environment can create a sensory overload causing anxiety and depression. For this part of the recovery process, it is important to know and understand that once easy activities will now be frustrating and exhausting; new approaches to old tasks are needed with extended time limits. The survivor and the caregivers will need coping strategies because this part of the recovery is stressful, and emotions are running high. If possible, a mental health councilor is recommended or a support group.

Outpatient Therapy

Outpatient therapy continues the rehabilitation process after a stroke, building upon the initial work done in inpatient settings. Outpatient stroke therapy provides ongoing rehabilitation for individuals recovering from a stroke after they leave the hospital. It involves scheduled therapy sessions at a clinic, therapist's office, or other outpatient facility, offering a range of therapies like physical, occupational, and speech therapy to improve functional abilities and independence. Therapy plans are tailored to the specific needs and goals of each stroke survivor. Like the team the survivor had in the inpatient rehabilitation hospital this new team of physical, occupational and speech therapist create a new set of goals to follow, which are likely towards independent living and returning to work and dependent of the age the stroke survivor. Outpatient stroke therapy is usually a six month plan or lasts as long insurance is provided or until goals are reached. Outpatient stroke therapy provides a more intensive and personal goal driven program by proving strategies and tools. Outpatient therapy provides an orientation to living and learning from the social diagnosis of the stroke. At the midway point of therapy or at three months the survivor and his or her therapists go out for a field trip to explore and experience accessible places in the community.

Going Solo-Independent

This last phase of the recovery plan the survivor incorporates all the skills and strategies learned in their months of therapy and slowly returning to their personal post-stroke goals. In this phase I recommend the survivor keep a journal and record areas that were difficult and frustrating and return to the journal and create a new plan to avoid difficulties in the future. For example, being better prepared by knowing the geography of the accessible parking, time management and raising the awareness to the people involved in your daily activities that you are disabled and may need some assistance. This phase is never fully completed as this will be a lifetime of living and learning with a disability.

Conclusion

Going back over my study with a thicker curriculum lens, I clearly saw my two different curriculum of recovery one official and one lived. The lived curriculum was made personal and meaningful because it focused on my needs, values and strengths. I saw the convergence and the divergence of the medical diagnosis of stroke and the social diagnosis when I placed them side by side and compared the two. The individualized stroke curriculum I created is one that I would have preferred to have experienced.

A stroke is a traumatic experience for anyone. I hope my story provides support and guidance for other fellow stroke survivors.

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