HAVING, BEING, AND LIVING:

STORIES OF DISABILITY BY WOMEN ATHLETES AFTER SPINAL CORD INJURY

by

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A Dissertation Submitted in

Partial Fulfillment of the

Requirements for the Degree of

Doctor of Philosophy

in Health Sciences

at

The University of Wisconsin-Milwaukee

August 2025

ABSTRACT

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The University of Wisconsin-Milwaukee, 2025
Under the Supervision of Professor Monna Arvinen-Barrow

Current research on women athletes’ experiences of psychosocial adaptation following spinal cord injury (SCI) remains limited, as highlighted by a recent systematic review (Zike et al., 2024). This research gap is significant, as women encounter distinct societal challenges stemming from overlapping systems of oppression, such as ableism and sexism (Garland-Thomson, 2001). The purpose of this research was to explore experiences of psychosocial adaptation to acquired disability in women athletes after SCI by documenting the meaning of (a) *having a disability*, (b) *being disabled*, and (c) *living with disability* in an ableist world. Study one aimed to explore the disability narratives of women athletes after SCI and document the meanings they attribute to experiences of psychosocial adaptation to acquired disability. Employing a narrative inquiry approach (Riessman, 2008), nine participants completed a virtual, semi-structured interview. Data were analyzed using an iterative, inductive, dual-narrative process consisting of both categorical-content and structural analysis (Lieblich et al., 1998). Four narrative types were identified: (a) *Attachment to a Nondisabled Past*, (b) *Push for Recovery*, (c) Em*bracing Life Without Embracing Disability*, and (d) *Transformation Through Shared Experience*. Study two provided women athletes with SCIs a visual voice to capture the

elements that shape their everyday life experience of (a) *having a disability*, (b) *being disabled*, and (c) *living with disability* in the community. Employing a Photovoice approach (Wang & Burris, 1997), six participants captured photographic images with personal cameras to illustrate the meaning of disability in their everyday lives. After two weeks of photo-taking, participants completed a virtual semi-structured interview to discuss the meanings represented in the images. The data were analyzed using Tsang's (2020) Photovoice data analysis method. Eight themes were captured: (a) *Taking Care of the Disabled Body*, (b) *Continuity and Attachment*, (c) *The Disability Tax*, (d) *Adaptations*, (e) *Interpersonal Connections*, (f) *Environmental Accessibility*, and (g) *Feeling Like a Disabled Person*, and (h) *Gratitude*. The results from studies one and two emphasize the complexity of the disability experience by characterizing it as multidimensional, dynamic, situational, contextual, and social-relational in nature. The results show that *having a disability* means embodying disability stigma and demonstrate the autonomous agency of women athletes as they navigate living with disability. The results also illustrate the interconnectedness of *having a disability*, *being disabled*, and *living with disability*, stressing the need to understand these components collectively when exploring psychosocial adaptation experiences related to acquired disability.

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To

my parents,

my brothers,

and my grandmother

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ACKNOWLEDGEMENTS

As this experience comes to an end, I am grateful for the many people that supported me and I want to acknowledge their contributions to this project. First, I would like to profusely thank my advisor Dr. Monna Arvinen-Barrow for so many things. Your consistent support from the beginning has been instrumental in my ability progress in my studies, writing, and development as a student, professional, and person. I could not ask for a better person to have in my corner.

I would also like to thank my committee members Dr. Barbara Meyer, Dr. Roger Smith, Dr. Christy Greenleaf, and Dr. Kara Ayers for your guidance in shaping this project. Your contributions have helped craft this, the final product of much time, effort, study, communication, interpretation, and determination.

I am grateful for my research participants, both those who participated and contributed to the research presented herein and those whose participation and contribution were instrumental in piloting this research and shaping the final product.

I am grateful for my critical friend Dr. Danielle Fleming for your patience, feedback, and thoughtful consideration of my ideas and interpretations.

I am grateful for my fellow students that have come and gone through PAV 375: Jess, Kenny, Carly, Becca, Rudi, Eddie, Chloe, Landon, Anthony, Jordan. Your advice, support, conversation, laughter, and community were indispensable throughout this long adventure.

I am grateful every day for my family—Mom, Dad, Taylor, Sam, Grandma, Holly, Sophie, Winston, and Dottie—and friends and their love, support, and encouragement throughout this process. You helped me when I was down, when my chair(s) were broken, when I crashed my car, when I was sick, tired, and in pain. You were there to listen and you provided the care and practical support that helped me navigate the many challenges.

Chapter I: Introduction

1.1. Disability

According to the Centers for Disease Control and Prevention (CDC), a disability is any condition of the body or mind that makes it more difficult for the person with the condition to do certain activities and interact with the world around them (Centers for Disease Control and Prevention, 2022). As specified in the Americans with Disabilities Act of 1990, a person with a disability is a person who has a physical or mental impairment that substantially limits one or more major life activities, has a record of such an impairment, and is regarded as having such an impairment (Tucker, 1992). These definitions, in place at the leading public health organization and in the landmark disability legislation of the United States of America (USA), both affect and reflect societal understandings of disability.

Throughout history, the treatment of and societal attitudes toward people with disabilities have been characterized by fear, intolerance, prejudice, and ignorance (Marini, 2011a). Disability has been considered a punishment from a higher power for sin or misbehavior, a sign of a perceived moral wrong, and a sign of sickness or a defect that should be medically cured or fixed (Retief & Letšosa, 2018). The disability rights movement challenged negative attitudes and stereotypes, coming together to support political and institutional change and lobbying for the disability community's self-determination (Patterson, 2018). The movement has been responsible for many legal achievements over the years, including passing the Section 504 regulations of the Rehabilitation Act of 1973 and the Americans with Disabilities Act (ADA) of 1990 (Patterson, 2018). These laws were passed largely due to the concerted efforts of disability activists protesting for their rights (Patterson, 2018).

The regulations for Section 504 of the Rehabilitation Act of 1973 were signed in 1977 after protests across the country organized by the American Coalition of Citizens with Disabilities (Heumann, 2020). Famously, disability rights activists led by Judy Heumann, Kitty Cone, and Brad Lomax engaged in a sit-in at the federal building of the Department of Health, Education, and Welfare (HEW) located in San Francisco that lasted nearly a month (Heumann, 2020). These activists persisted, and not a single person chose to go home until the regulations were signed. The signing of Section 504 was historic because it was the first piece of civil rights legislation to specifically address the rights of people with disabilities. It also signified the first time that people with disabilities were considered a legitimate minority group, one that could be subject to discrimination and deserving of civil rights protections (Mayerson, 2008).

The passing of the Americans with Disabilities Act (ADA) of 1990 was another monumental civil rights achievement for people with disabilities. The ADA prohibits discrimination against people with disabilities in many aspects of public life (Scotch, 2000). On March 12th, 1990, a critical event led to the passage of the ADA. Disability rights activists gathered at the steps of the United States Capitol building; casting aside their wheelchairs, walkers, and crutches, they ascended the steps in what became known as the "Capitol Crawl" (Ginsburg & Rapp, 2017). This protest was intended to illustrate the daily struggles of people with disabilities due to physical barriers and highlight the need for accessibility. Despite disability rights legislative achievements, progress in achieving equality for people with disabilities has been slow (Abrams, 2020; National Council on Disability, 2007). Although gains have been made, attitudinal and environmental barriers and social disparities persist in many areas.

Today's society continues to prioritize healthy, abled, neurotypical, and biotypical bodies (Friedman, 2019; Rojas, 2022; VanPuymbrouck et al., 2020). This is reflective of how pervasive and entrenched ableism is in our society. The leading societal discourse continues to devalue disability (Ahlvik-Harju, 2016). Culturally dominant narratives frame disability as something to be overcome or an individual tragedy (Campbell, 2009; Loja et al., 2013; Oliver, 1996), and, of these narratives, ableism remains situated as the dominant disability narrative in Western society (Ahlvik-Harju, 2016). According to Campbell (2001), ableism is "a network of beliefs, processes, and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human" (p. 44). Those who deviate from this standard find themselves on the pathway to disability (Campbell, 2009). People with disabilities have expressed several ways in which the effects of ableism have been socially and psychologically damaging (Bell, 2013; Ostrove & Crawford, 2006). In Loja and colleagues (2013) study on the impact of ableist discourses about impaired bodies on people with disabilities, they found that as people with disabilities narrate their experiences, they must confront ableism. In doing so, they must negotiate with the normative standards of ableism that produce "acceptable" bodies.

1.2. Gender and Disability

Gender refers to the socially constructed meanings we ascribe to being a man, woman, or gender diverse (Aleshire, 2016). Masculinity and femininity refer to a set of characteristics, practices, norms, and roles we typically associate with being a man or woman, respectively (Kachel et al., 2016). How we define what is masculine or feminine varies across cultures and can change over time, and, as such, masculinity and femininity come in many forms (Schippers,

2007; Twenge, 1997; van de Vijver, 2007). In Western society, there is a privileged or hegemonic conceptualization of masculinity that operates to guarantee the dominant position of men through the subordination of women, femininity, and other masculinities (Anderson, 2005; Connell, 1995; Krane, 2001; Krane et al., 2004; Ross & Shinew, 2008). This concept of hegemonic masculinity is a cultural ideology that legitimizes and reinforces an idealized notion of what constitutes masculinity or "manliness." As an overarching framework guiding the gender hierarchy of society, hegemonic masculinity marginalizes women and frames femininity as a deviation from the norm.

Cultural expectations of masculinity dictate that men should be independent, breadwinners, stoic, athletic, aggressive, confident, dominant, and tough (Charmaz, 1994, 1995; Marini, 2007; Ross & Shinew, 2008). These expectations are the polar opposite of those for women. Cultural expectations of femininity dictate that women should be beautiful in physical appearance, passive, compliant, nurturing, homemakers, and unsure of themselves (Connell, 1987; Hwang, 1997; Ross & Shinew, 2008). Hegemonic conceptualizations of masculinity and femininity also frame cultural understandings of the body (Anderson, 2005; Krane, 2001; Krane et al., 2004; Ross & Shinew, 2008). The ideal masculine body is expected to have large, toned, well-defined muscles, while the ideal feminine body is expected to be thin and slender yet toned and lean (Dworkin, 2001; Grogan et al., 2004; Krane et al., 2004; Markula et al., 2008; Swami, 2015). These differences in expectations of what is masculine and feminine influence how men and women are perceived and guide behavior. Those that deviate from these expectations are viewed as abnormal.

While women deviate from the societal standard of hegemonic masculinity, having a disability means they also deviate from the socially constructed ideal of femininity. Gill (2007) explains that femininity is represented in contemporary media culture mostly as an attribute of the body rather than a social, structural, or psychological quality. As such, women are closely associated with their bodies. The inability of their bodies to live up to the cultural requirements of ideal femininity presents a dilemma for women with disabilities. According to Garland-Thomson (2002, p. 17), women with disabilities are “removed from the sphere of true womanhood and feminine beauty.” Research has shown that cultural narratives of disability frame women with disabilities as helpless, asexual, unsuitable for motherhood, and inadequate for traditionally female roles (Fine & Asch, 1988; McDonald et al., 2007). In effect, societal expectations of femininity invalidate women with disabilities’ status as women.

It is apparent that women with disabilities face unique challenges due to the intersection of their disability and gendered experience. According to Garland-Thomson (2001), cultural expectations, attitudes, and social institutions create material conditions in which people who are classified as women and having a disability are twice marginalized. This means that systems of inequality based on both gender and disability overlap to create a unique pattern of oppression. Kimberlé Crenshaw (1989) created the term intersectionality to specifically highlight the multiple compounding forms of oppression that women with disabilities may experience. Originally conceived to demonstrate the obstacles that Black women encounter in employment, Crenshaw explained that in a situation at a company where only White women were being offered office and secretarial jobs and only Black and White men were being offered factory jobs, Black women, in effect, became invisible – suffering double

marginalization and exclusion (Crenshaw, 1989). Due to this, when investigating situations where an individual exists at the intersection of two or more vulnerabilities, the focus should be on the interplay of these vulnerabilities (e.g., gender, disability, race) rather than one in isolation.

It is evident that societal expectations of masculinity and femininity, as well as the proliferation and internalization of societal attitudes around gender and disability, create obstacles for women with disabilities (Nosek & Hughes, 2007). Unable to meet societal expectations of masculinity or femininity, women with disabilities are, in effect, made invisible, which consequently masks the discrimination they face (Meekosha, 2004; Yates et al., 2021). These obstacles may not be readily apparent if one were to direct their focus towards the gendered or disability experience in isolation. The obstacles created by society to enact power over women with disabilities may also present an opportunity. Since women with disabilities do not align with the stereotypes of women in Western society, some believe they may have the ability to be who they truly are as women (Lisi, 1993). In other words, since society rejects them, women with disabilities may be capable of truly exploring who they are. Regardless of whether these women pursue, abide by, or reject the social expectations and traditional gender roles that exclude them, the complex interplay between gender and disability presents important psychosocial issues to explore further.

1.3. Sport, Gender, and Disability

Sport is a microcosm of society (DePauw, 1997; Hylton et al., 2020). As a social institution, sport reflects and reinforces the dominant cultural norms, standards, and ideologies within society in a manner that creates unequal power relationships (Hall, 1997; Hargreaves,

1994; Jhally, 1989; Sage, 1990). Scholars have asserted that the cultural ideology of hegemonic masculinity is maintained, reinforced, and perpetuated through sport (Connell & Messerschmidt, 2005; Messner, 1989, 1990, 1992). This ideology is instrumental in directing the focus of sport towards "bodily superiority through aggression, competition, an us-vs-them mentality, and dominance" (Krane & Waldron, 2020, p. 4). The sports arena provides a continuous display of men's bodies in action. This exhibition of masculine power allows for the exercising and legitimizing of male hegemony (Eitzen, 2000). Sport has continued to be considered a masculine domain (Clément-Guillotin et al., 2012) that demands the emphasis of stereotypically masculine characteristics and behaviors (e.g., strength, aggressiveness, competitiveness) to be successful (MacDonald, 2014; Plaza et al., 2017). As such, sport participation has provided a masculinity-validating experience to men. Through sport, men have the opportunity to learn how to achieve a masculine identity (Harris, 1995) and experience social acceptance (Ross & Shinew, 2008).

Women have faced marginalization, resistance, stigmatization, and trivialization in their attempts at constructing meaningful sport experiences (Blinde & McCallister, 1999; Kane, 1996). Women in sport find themselves in a challenging position as they are situated at the intersection of two contrasting ideals of the body: (a) cultural standards of femininity and the ideal feminine body (e.g., thin, slender, absence of musculature; Grogan et al., 2004) and (b) sport-related understandings of the ideal athletic performative body (e.g., muscular, strong, nondisabled; DePauw, 1997; Hardin et al., 2002). These contrasting ideals concurrently constrain women athletes through social pressure to conform to societal expectations of femininity and masculine notions of muscularity necessary for athletic performance (Krane,

2001). This intersection creates a tension between cultural standards of femininity and athleticism that women athletes must navigate both on and off the field in order to be accepted in Western culture.

Krane and colleagues (2004) refer to this tension or dilemma as the "female/athlete paradox." Women athletes are expected to succeed in sport while maintaining traditional standards of femininity and the female body (Dworkin, 2001; Krane, 2001; Krane et al., 2004; Ross & Shinew, 2008). Their participation in sport is deemed socially (un)acceptable depending on how well they conform to these standards (Gniazdowski & Denham, 2003; Tuggle & Owen, 1999). However, in order to be successful in sport they have to develop characteristics associated with masculinity (e.g., strength, competitiveness, assertiveness, independence; Krane, 2001). The display of masculine characteristics (e.g., power, strength) by women in sport is often construed negatively because these displays are often thought to contradict femininity (Krane et al., 2004). When women athletes sweat, play aggressively, wear athletic wardrobes, develop muscles, or have masculine builds, they are perceived as failing to meet societal standards of femininity (Krane et al., 2004).

It is apparent that women in sport tread a fine line in maintaining acceptable femininity (Krane, 2001). According to Sparkes and colleagues (2014), the ideal female sports body is expected to be "firm but shapely, fit but sexy, strong but thin, and… able-bodied" (p. 7), a body that does not challenge standards of femininity. Women athletes have described an arbitrary line between what is an attractive muscular body and a body that is "too muscular" that enables them to somewhat negotiate the tension between ideal bodies (Krane et al., 2004). However, this can be a difficult line to negotiate and maintain. Previous studies have

highlighted women athletes' dissatisfaction with their muscular bodies and the weight associated with large muscle mass (Bennett et al., 2017; Krane et al., 2004). Some women athletes report a desire to change their bodies aesthetically to increase compliance with the feminine ideal (Bennett et al., 2017). Women have attempted to manage conflicting societal expectations through a number of strategies. In their efforts to maintain femininity within their athletic role, women athletes have discussed engaging in compensatory behaviors (e.g., wearing makeup, ribbons, dresses), both inside and outside of sporting contexts, to reinforce the notion that they are feminine (e.g., Krane et al., 2004; Ross & Shinew, 2008). Some women in sport attempt to avoid negative stereotypes by trying to prevent an increase in muscle mass or, in some cases, ceasing participation altogether.

Women who retire from sport still experience the tension of the female athlete paradox. Retired women athletes have reported experiencing a conflict between their bodies shifting towards feminine ideals while at the same time moving away from their former muscular, athletic physique (Papathomas et al., 2018). They may describe these bodily changes and reduction in muscle mass as positive, marking a shift towards femininity, or negative, marking a shift towards increased body fat and away from muscularity. Previous research has demonstrated that some former women athletes become even more satisfied with their bodies post-retirement, as reductions in muscularity bring them closer to the thin, feminine ideal (Papathomas et al., 2018). Other retired athletes who judge their current bodies against their previous athletic bodies and view the resulting discrepancy negatively have experienced greater body dissatisfaction (Greenleaf, 2002). Athletes who subscribed to both an athletic ideal and a feminine thin ideal represent particularly complex cases, as the fulfillment of one ideal would

result in the nonfulfillment of the other. Commitment to two incompatible body ideals may render a retired woman athlete at risk of prolonged body dissatisfaction (Papathomas et al., 2018).

The disabled body often does not meet the guidelines of the “ideal sporting body” (Hardin, 2003). Perceptions of the disabled body as weak, passive, and dependent further distance it from the sport domain (DePauw, 1997). Sport as a place of admiration of physicality presents a challenge for disabled women athletes (DePauw, 1997). The association of the female body as weak combined with the notion of a disabled body as disempowered would suggest that a woman with a disability cannot and should not participate in sport. However, in a study of adults who participated in a wheelchair sport camp, Ashton-Shaeffer, Gibson, Autry, and colleagues (2001) found that participation in sport allows for resistance and empowerment. This suggests that women with disabilities have the opportunity through sport to challenge socialization and create new opportunities for themselves. In addition, Ashton-Shaeffer, Gibson, Holt, and colleagues (2001), in a study of women members of the national wheelchair basketball team, found that the women’s experiences had given them the opportunity for resistance to society’s perceptions of disability. Their experiences empowered them to recognize their bodies as instruments of power in challenging preconceived notions of the abilities of people with disabilities. Thus, disability sport may present unique opportunities for disabled sportswomen. The intersection between sport, gender, and disability creates a complex milieu in which women with disabilities must navigate. Understanding this intersection is important in order to make sense of women's experiences in and as they exit the realm of sport with a spinal cord injury.

1.4. Spinal Cord Injury

An acquired disability is associated with health conditions and impairments that originate after birth, not caused by hereditary or developmental factors (Waldman et al., 2016). The onset of acquired disability is often linked to traumatic injury or disease (Livneh & Antonak, 2005). Spinal cord injury (SCI) is a neurological condition usually caused by a sudden, traumatic impact that fractures and/or dislocates the spine, resulting in bruising, partial rupture, or complete severing of the spinal cord (Crewe & Krause, 2009). According to the National Spinal Cord Injury Statistical Center (NSCISC), the annual incidence of SCI in the United States is approximately 54 cases per one million people, or about 17,810 new cases each year (NSCISC, 2020). Of new cases, approximately 22% occur in women, while 78% occur in men (NSCISC, 2020). The total number of SCI cases in the United States is estimated to be around 294,000 (NSCISC, 2020). Although the incidence of SCI is relatively low, the impact of this condition on the individual is substantial.

In short, a SCI is life-altering. acquiring a SCI can dramatically change an individual's biological body and their psychological and social worlds (Cole, 2004). Common physical consequences of SCI include partial or complete paralysis; loss of mobility; loss of sensation; chronic neuropathic pain; spasticity; osteoporosis; pressure sores; and impaired bowel, bladder, sexual, and/or respiratory function at or below the site of injury (Gensel, 2014; Sezer et al., 2015). Psychological consequences of SCI include higher levels of depression and anxiety, post-traumatic stress disorder, and lower life satisfaction (Craig et al., 2009; Migliorini et al., 2008; Post & van Leeuwen, 2012). Individuals with SCI are at increased risk of social consequences such as social isolation and social disconnectedness (Geyh et al., 2012; Guilcher

et al., 2019). They also have greater difficulty with community integration (McKinley & Meade, 2004). It is clear that Individuals face numerous challenges to their health and well-being due to the sudden and significant changes brought about by acquired SCI. Given that those who acquire a SCI are often young in age, the average age at the time of injury is around 37 years old (DeVivo & Chen, 2011), individuals with SCI are likely to face challenges for many years.

In addition, SCIs typically have significant financial implications. Due to the extreme nature of a SCI medical event, costs associated with acute and emergency care can be extensive. The average cost for a SCI hospitalization was found to be $142,366, which is more than four times the cost of non-SCI hospitalizations (Mahabaleshwarkar & Khanna, 2014). The average length of hospital stay following SCI is twice as long as patients without SCI (Mahabaleshwarkar & Khanna, 2014). Re-hospitalization rates are also high among those with SCI. About 30% of people with SCI are re-hospitalized one or more times during any given year following injury (Krause et al., 2019). For those re-hospitalized, the average length of hospital stay averages about 22 days. Costs associated with acute and emergency care can quickly balloon into hundreds of thousands of dollars.

Costs associated with post-acute care and the lifetime management of SCI can also have significant financial implications. The lifetime costs of managing SCI for an individual injured at age 25 can range from about $1.6 million to $4.9 million, depending on severity (NSCISC, 2020). This represents a significant financial burden on the person. Depending on the severity of the injury, the average expenses (healthcare costs and living expenses) in the first year following an injury can range from $359,783 to $1,102,403 (NSCISC, 2020). In each subsequent year, the average yearly expenses can range from $43,700 to $191,436. The financial burden of SCI is also

felt at the macro level. Annual costs attributed to SCIs have been estimated to be approximately $9.7 billion in the U.S. alone (Berkowitz et al., 1998). Individuals with SCI and their families must carry a hefty financial burden. Due to very low chances of medical recovery (Khorasanizadeh et al., 2019), these individuals must learn to manage and minimize this burden. The financial implications of living with impairment and disability are well documented (Goodman et al., 2020; Olsen et al., 2022). The impact the financial burden of SCI may have on the experience of psychosocial adaptation to disability presents a path for further exploration.

The sudden onset of impairment and disability as a result of SCI constitutes a psychosocial crisis (Livneh & Antonak, 1997; Moos & Schaefer, 1984). Individuals with SCI must adapt to the uncertainty, changing demands, and psychosocial consequences of this crisis. Research on the psychosocial adaptation experiences of athletes who acquire a SCI is limited (*n* = 12) (i.e., Goraczko et al., 2020; Rees et al., 2003; Smith, 2013; Smith & Sparkes, 2004, 2005, 2007, 2008; Sparkes & Smith, 2002, 2003, 2008, 2013; Zurek et al., 2022). Of the published research in this area, the lived experiences represented come from a largely homogenous sample of white, heterosexual men living in the United Kingdom. Women athletes who have acquired a SCI have been poorly represented in the literature. A total of five studies were found to *include* women athletes who have acquired a SCI as participants in investigations of psychosocial adaptation to disability (i.e., Goraczko et al., 2020; Hawkins et al., 2014; Tasiemski & Brewer, 2011; Wu & Williams, 2001; Zurek et al., 2022). Women athletes' lived experiences of psychosocial adaptation to acquired disability after SCI is an area in need of further research. This represents a gap in our understanding of acquired disability and indicates there may be potential issues with how we approach women athletes with SCI.

Existing research has established that women exiting nondisabled sport due to impairment and acquired disability exist at an intersection of disability, gender, and sport that presents complex issues to be addressed (DePauw, 1997; Hardin, 2007). Therein lies the problem. What we know about this experience is primarily from a man's perspective. Simply accepting current conceptualizations and applying them to women with a disability may negate the experiences of women with disabilities, ignoring important aspects of women's gendered experience. Women athletes with SCI and their stories of adaptation to acquired disability must be heard and explored to understand their experience better.

1.5. Focus

This research focuses on the psychosocial adaptation experiences of women athletes after SCI. Specifically, this research will focus on three aspects of the SCI and acquired disability experience: (1) *having a disability*, (2) *being disabled*, and (3) *living with disability*. It is important to explore stories of *having a disability*, *being disabled*, and *living with disability* told by women athletes who have acquired a SCI, and the meanings constructed within. The stories that are told and the meanings constructed around disability help shape experiences of adaptation to acquired disability.

The three foci of the proposed research represent various stories told about acquired disability and how one adapts to the psychosocial challenges of SCI. The personal stories one tells communicate one's experiences and can reflect one's psychological reality (Smith & Monforte, 2020), but their stories do not emerge solely from the individual's mind. Stories about acquired disability are socio-culturally derived from the narratives that one's culture provides. According to Baldwin (2013), dominant cultural narratives, such as ableism, challenge

the telling of alternative stories about disability. Dominant narratives can “narratively dispossess people” or “prompt narrative foreclosure” (Baldwin, 2013, p. 106). To fully understand the stories of adaptation to acquired disability told by women athletes after SCI, we must explore how their stories are constructed in the face of ableism.

1.6. Purpose Statement

The purpose of this research is to explore experiences of psychosocial adaptation to acquired disability in women athletes after SCI. In particular, this research will investigate the meaning of (a) *having a disability*, (b) *being disabled*, and (c) *living with disability* in an ableist world.

1.7. Specific Aims

- Aim 1: To explore the disability narratives of women athletes after SCI, and to document the meanings they attribute to experiences of psychosocial adaptation to acquired disability.
- Aim 2: To provide women athletes with SCIs a visual voice to capture the elements that shape their everyday life experience of (a) *having a disability*, (b) *being disabled*, and (c) *living with disability* in the community.

1.8. Research Questions

Aim 1: Research questions:

1. What does it mean to women athletes who have acquired a SCI, in their experience of psychosocial adaptation to acquired disability, to have a disabled body in an ableist society?

2. What does it mean to women athletes who have acquired a SCI, in their experience of psychosocial adaptation to acquired disability, to be disabled in an ableist society?
3. What does it mean to women athletes who have acquired a SCI, in their experience of psychosocial adaptation to acquired disability, to live with disability in an ableist society?

Aim 2: Research questions:

1. How do women athletes who have acquired a SCI capture the elements that shape their everyday life experience of *having a disability* in the community?
2. How do women athletes who have acquired a SCI capture the elements that shape their everyday life experience of *being disabled* in the community?
3. How do women athletes who have acquired a SCI capture the elements that shape their everyday life experience of *living with disability* in the community?

1.9. Delimitations

This research will only include persons who self-identify as women. This research does not cover men as the purpose is to explore the experiences of women athletes after SCI due to the lack of research investigating women with SCI. This research will also only include individuals aged 18 years old or older. Youth under the age of 18 years old have been excluded from this research to standardize the recruitment procedures for each participant and ensure a certain degree of maturity of responses obtained in the data. This research is limited to individuals who are at least two years removed from the injury occurrence. Individuals will be excluded from this research before they are two years removed from the date of injury to make

sure that participants are not included until they have time to process their injury and newfound disability. Individuals that live outside of the United States have also been excluded from this research. As this research will explore the narratives of women's experiences with psychosocial adaptation to acquired disability, it will be important to understand the dominant socio-cultural narratives that influence their personal stories. Standardizing the culture in which participants live will simplify the analysis of data and limit potential cultural misunderstandings on behalf of the researcher. Participants will be excluded if they do not speak English because the researcher only speaks English, and if a participant spoke a different language exclusively, it would hinder data collection.

1.10. Limitations

It is possible that the sample of participants included in this research would be biased insofar as only individuals who have had positive adaptation experiences may feel able and/or willing to share their insights. The brief photo-taking period in Study 2 is also a limitation as the researcher is unable to address how concepts such as identity may change over time and the circumstances that lead to such changes.

1.11. Assumptions

It is assumed in conducting the current research that participants will (a) respond to questions honestly; (b) not mischaracterize themselves; and (c) knowledge gained from this research will benefit people with disabilities, particularly those acquired through SCI.

1.12. Practical Significance

The present research will help by increasing awareness of the narratives told by women athletes after SCI and the narrative elements that shape the adaptation experience. This

research will also provide a voice to women athletes who have acquired a SCI and the agency to tell their own story. As a person (and researcher) with a disability, I bring an important insiders perspective to direct research towards important areas and conceptualize this research in a way that a nondisabled researcher may not. This is the first research to conceptualize the collective acquired disability experience by jointly examining the existing research and literature on having, being, and living with disability. The findings from this research will help guide future research of women with acquired disability.

Chapter II: Reflexivity

Reflexivity is the practice of situating oneself in the research context through a process of critical reflection (Nolas, 2011). This practice involves analyzing the implications of one's subjectivity for the research context and the research being carried out. It also involves scrutinizing and critiquing the assumptions one makes about the research. My position is that of a disabled, white, heterosexual, cisgender man with a personal history of acquired sporting SCI. I have a physical disability (quadriplegia) acquired in my late adolescence in an ice hockey accident. The acquired disability serves as the primary motivation for investigating this topic. Given the life story that I bring to the process of collecting, interpreting, and representing the stories of others with disabilities, I must establish my positionality and take steps to mitigate any issues this might cause. For me, having a disability means that I exist within an impaired body, which I use to act, communicate with others, and experience the world. I say that I am a disabled person because disability is an inextricable part of my self and a valued identity. Being disabled shapes how I see myself, my body, and my interactions with the social and physical world. Living with an acquired disability means that I have known how it is to live as a nondisabled person. I have experienced the loss of valued life roles and identities. I have also experienced radical bodily changes that have often led to recurrent frustrations and periods of sorrow with my body and my surroundings. Living with disability has also meant continuing to strive for acceptance and access as well as growing from my disability experience. Disability has meant that I continue to run into barriers, both attitudinal and physical, that try to tell me that I do not belong. It also has been a source of joy, expression, and some of my most rewarding and exciting life experiences.

There are several ways in which *having a disability*, *being disabled*, and living with disability may facilitate or hinder my work as researcher in the research process. *Having a disability* means that I have an insider's perspective on the disability experience. Having a *visible* disability means that I am likely to be treated as an insider by individuals with disabilities that take part in the research process. These people may find it easier to trust me with sensitive information. As a result, I may be given greater access to insightful information about their experience. Having a disability also means that I feel empathy and compassion for, and recognize the experiences of, other people with disabilities. This may influence how I interpret the accounts of others, giving me the ability to understand the nuance in meaning participants apply to having a disability. *Being disabled* and conducting disability research has sensitized me to aspects of this experience that may be illuminated during investigation. My identity and background offer opportunities to relate to anticipated participants. The development of a positive disability identity and the pursuit of advocacy has given me greater opportunities to connect to the disability community. My unique perspective gained from *living with disability* may allow me to conduct research in a more sensitive and accessible manner as I understand many of the barriers and facilitators to carrying out the research process. This means I am aware of what may make it more difficult for a person to participate and how to go about facilitating their participation.

Seeing as my interest in disability research revolves around bodies similar to mine, having an acquired physical disability may represent a point of comfort for participants during the interview process. The comfort that participants feel due to our shared experience of physical disability may not always be a positive. There is the possibility that disabled people

may not feel the need to explain themselves or their experience in the same manner as they would with a nondisabled person – omitting important details that they assume I would innately understand. This feeling of comfort can go both ways in the researcher-participant relationship. There is the risk that my experience with acquired disability and comfort listening to stories of disability may influence the depth to which I probe for details in their story and how I interpret their responses.

Despite having a positive disability identity, I continue to believe that I lack a strong sense of collective disability identity. An ableist society exerts pressure on those who deviate from the norm, making it difficult for disabled people to accept their bodies and connect with the disability community (Campbell, 2008; Reel & Bucciere, 2010). I have navigated these pressures and the influence of internalized ableism for many years. This has meant that I lack many connections with my disabled peers, and I do not have regular interactions with others with disabilities. My lack of connection to the disabled community might make it challenging to develop a rapport with another disabled person. As a result, the researcher-participant relationship may suffer.

With my background, and the various identities that I hold or held (e.g., man, white, upper middle class, ice hockey player), a power imbalance may be created in the researcher-participant relationship. This imbalance may exist to varying degrees dependent on the compounding demographic factors of the participant. A power imbalance can negatively affect trust (Castleton et al., 2008) during data collection. Without trust between the researcher and participant, the participant may be reticent to discuss intimate details of their disability experience. As a person currently living with a disability, and who has been living with disability

for well over a decade, I have a privileged view of the processes of interest. This view may influence what I expect to hear in participant responses. Not all experiences of living with disability are the same, and, for that reason, I must be careful to not expect participant responses to confirm my own experiences or reject responses that do not fit my disability narrative.

To mitigate the above concerns, there are several solutions that I intend to implement. Early during the initial interview process, it is my goal to establish a degree of comfort and trust with the participants by engaging in reciprocity, which means sharing aspects of my story (Corbin & Morse, 2003). By revealing aspects of my experience with disability, it may give me, as the researcher, credibility in the eyes of disabled individuals (Olkin, 2004), which may facilitate rapport in carrying out the data collection procedures. This act may also make participants feel trusted and return disclosure as a sign of trust (Dindia et al., 2002).

As part of my data collection methods, I intend to ask participants to use disposable cameras to capture their experiences. The use of cameras in photo elicitation research has been observed to help correct power imbalances in the research process, in particular, as it relates to participants' potential contributions (Wang, 2000). While my research is not participatory action research, the use of cameras gives the participant greater power in deciding the data to be captured and discussed. I will give participants disposable cameras to capture that which represent the topics assigned. Using this method, I hope that participants will feel greater ownership of the research and investment in the data collection process.

During the data analysis phase of the research process, I will engage in peer debriefing to ensure interpretations of the data are plausible and defensible. Peer debriefing is a

technique in which the researcher's interpretations and initial themes are reflected to a critical friend (Barber & Walczak, 2009). A critical friend, not involved in data collection, will review transcripts and lists of themes to question and explore alternative interpretive possibilities. Critical friends encourage reflexivity and provide opportunities to challenge and defend interpretations (Cowan & Taylor, 2016, p. 508). Through dialogue with the critical friend, it is determined whether a case is defendable and if the interpretations made are plausible (Smith & McGannon, 2018). As suggested by Dahlgren and colleagues (2006), the critical friend should be, at minimum, at an equal knowledge level to the researcher to be capable of offering critique, facilitating discussion, and encouraging improvement. The critical friend will be a trusted colleague with Ph.D. expertise in a related field to the topic studied and experience conducting qualitative research. The use of peer debriefing will ensure that my perspective is not unduly influencing the results or misrepresenting the data provided by participants.

I will carry out member-checking (Creswell & Miller, 2000) after interviews and initial data analysis. Member-checking is "sharing interview transcripts, analytical thoughts, and/or drafts of the final report with research participants to make sure you are representing them and their ideas accurately" (Glesne, 2006). Sparkes and Smith (2014) suggest that participant feedback obtained through member-checking should not be taken as validation or refutation of inferences made from the data by the researcher. Instead, they recommend treating member-checking as another source of data and an opportunity to enhance one's understanding of how those involved in the research process co-construct the findings. This will be done by inviting participants to reflect on initial themes and interpretations of the data. Member-checking will help determine whether the data analysis is congruent with participants' experiences (Smith &

Osborn, 2008). It may also help cede power to participants by giving them greater authority over how their story is represented.

Throughout the research process, I will engage in writing a reflexive diary of the data collection and data analysis process. A reflexive diary provides me with an opportunity to document and reflect upon my thoughts during the processes of data collection and data analysis (Clancy, 2013). I have the opportunity to withdraw from the data and the research process as a whole and take the time to better understand how my perspective and experiences may influence the interpretation of data.

Chapter III: Literature Review

Consistent with the purpose of the proposed research, chapter III aims to explicate the need to explore the psychosocial adaptation to acquired disability of women athletes who have acquired a SCI and their stories of having a disabled body, being disabled, and living with acquired disability. The literature review presented herein will be divided into four distinct parts: (a) having (a disability), (b) being (disabled), (c) living with (a disability), and (d) a chapter summary of the literature to date. First, this review will introduce literature that defines what it means to *have a disability*. Here, it will be outlined for the reader the key models used to establish an understanding of *having a disability*. Empirical evidence that attests to what each of the models says about having a disabled body will follow. Second, the review will define what it means to *be disabled*. Readers will be presented with key models of disability identity, capturing the different conceptualizations of the ways that people form identities around disability. Identity models are used to encapsulate the personal and intrinsic parts of the self. Third, models and empirical evidence on *living with a disability* will be presented. Lastly, a synthesis of the reviewed literature will provide a rationale for the chosen methodology to be introduced in chapter IIII.

3.1. Having (a Disability)

To have means to hold, to possess, or be able to make use of (have, 2021). Every person has an objective, physiological body. We exist in these bodies and navigate them as we travel through our daily lives. The body is more than just a material, physical structure that carries a person's organs, bones, and flesh; it is through the body that one acts, communicates, and experiences the world (Merleau-Ponty, 1962). In other words, the body is the vehicle that our

conscious experience of the world relies upon (Joas, 1996). Embodiment is the lived experience of the body; the subjective, felt sense of the body; the bodily context from which one operates (Merleau-Ponty, 1962). Acquiring a disability as a result of illness or injury constitutes a profound disruption to the body that one possesses. One's embodiment is challenged by the disrupted body (e.g., Kumar & Menon, 2018). In the aftermath of SCI, individuals are tasked with remaking the body and engaging in a process of re-embodiment (e.g., Seymour, 1998). As they go about remaking the body, individuals with SCI must contend with the biological reality of having an impaired body as well as the effects of impairment and structural and psycho-emotional disablism (Thomas, 2004). Disablism is defined as "the social imposition of avoidable restrictions on the life activities, aspirations, and psycho-emotional well-being of people categorized as 'impaired' by those deemed 'normal'" (Thomas, 2012, p. 211). In the sections that follow, several models that aim to explain what it means to *have a disabled body* will be introduced: (a) the medical model (Szasz, 1956); (b) the social models (Hahn, 1985a; Tøssebro, 2004; Oliver, 1990); (c) the social relational model (Thomas, 1999); and (d) the international classification of functioning, disability and health (WHO, 2001).

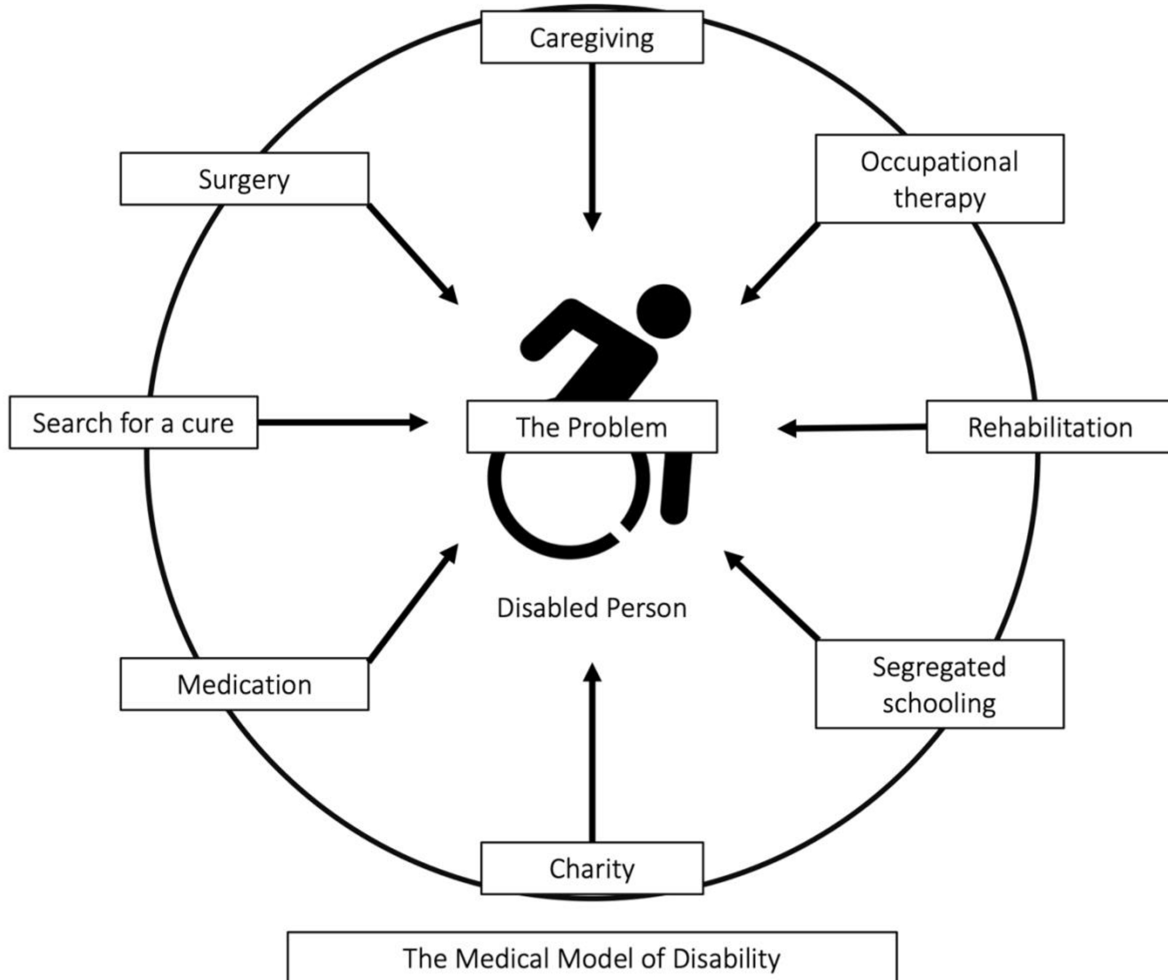
3.1.1. The Medical Model of Disability

Historically, the dominant way of understanding what it means to *have a disability* has been through the lens of the medical model, also referred to as the individual model of disability (Scotch, 2000). Coined by psychiatrist Thomas Szasz in the critique of his own field's construction of mental illness (Szasz, 1956), the medical model defines disability as "a medical problem that resides in the individual. It is a defect in or failure of a bodily system and as such is inherently abnormal and pathological" (Olkin, 1999, p. 26). According to the model, an

individual’s disability is an innate, biological trait that can be managed or cured by medical professionals (Crossley, 1999). As portrayed in Figure 1, the individual is placed at the center of the model, where parts of the body affected by impairment are labeled “the problem” of disability. By doing so, the medical model presumes having a disability to be a medical problem in need of an individualized medical solution (Crossley, 1999). The “problem” of disability is surrounded by an array of possible solutions. In general, appropriate solutions to having a disability fall under one of two categories: (a) medical efforts to cure or remedy the trait effects of disability (i.e., medication), or (b) services that minimize the effects of having a disability (e.g., rehabilitation efforts that enable the individual to overcome the effects of the disability, caregiving; Crossley, 1999).

Figure 1

The Medical Model of Disability



The medical model of disability relies on biophysical assumptions of normality (Smith & Bundon, 2018). By doing so, having a disability is seen as a deviation from normal health status. In effect, this means that people with disabilities are considered unhealthy and in need of medical intervention. The medical model's definition of disability is fundamentally negative. It presumes that having a disability is a personal tragedy (Carlson, 2010). Under this view, having a disability is assumed to be an indication of a personal flaw to be hidden, removed, or cured.

The individualized nature of disability in the medical model characterizes having a disability as one's personal misfortune (Crossley, 2003; Scotch, 2000). Any efforts by society to respond to disabled people are thus characterized as charitable efforts to address an individual's "neediness." Medical model conceptualizations of disability solutions essentially assume that disabled people are passive receivers of services that aim to cure or manage the problem (Crossley, 1999). This, in effect, ignores the agency of individuals who have a disability.

Few studies have explored the applicability of the medical model on *having a disability* (Alve & Bontje, 2019; Brittain, 2004; Jaarsma et al., 2014; Jaarsma et al., 2016). In a sample of Paralympians (*n* = 12), Brittain (2004) examined the impact of societal perceptions of disability. He found that disabled individuals and those close to them demonstrated perceptions that are consistent with the medical model, in that having a disability is negative and a biological imperfection. These perceptions were also found to be connected to beliefs that disabled individuals are (a) unable to do tasks they had done before having a disability and (b) incapable of taking part in sport or strenuous physical activity. As a result, having a disability had the potential to undermine Paralympian's close relationships, increase feelings of being a burden to others, engender derision when professing aspirations to achieve in sport, and ultimately inhibit sports involvement. The findings by Brittain also appeared to support Drake's (1999) claim; that those who have a disability and unconsciously accept the medical model will strive for individual change (i.e., change within the person) over social change (i.e., change in environmental conditions, societal perceptions). More recently, Alve and Bontje (2019) examined factors that influence participation in daily activities by persons with SCI. Their results are consistent with the medical model; as a majority of what we know about barriers

and facilitators of participation in daily activities pertains to long-term physical health and functional capacities, self-efficacy and adjustment skills, relearning capacities for performing daily activities, and availability of cost-effective adaptive equipment. Essentially, factors internal to the individual. Meanwhile, other studies have demonstrated the influence of medical model discourse on the perceptions of people with disabilities as children and adults reported "the disability itself" or "their disability" as barriers to sport participation (e.g., Jaarsma et al., 2014; Jaarsma et al., 2016).

The medical model has stood for over a hundred years as the dominant paradigm for understanding *having a disability* (Stotch, 2000), and to this day remains entrenched in popular culture and legal commentary (Areheart, 2008; Hamilton, 2019). However, currently, it is difficult to find any contemporary scholars as proponents of the medical model (Areheart, 2008; Shakespeare et al., 2006). Rather, the model has traditionally been used as a way of describing the Western societal norms that have anchored understandings of *having a disability* in medicalization, prejudice, and the devaluation of disabled people (Areheart, 2008; Shakespeare et al., 2006). Researchers in the domain of sport and exercise have argued that research in disability sport is, at times, framed by medical model discourse (Smith & Perrier, 2014). Haslett and colleagues (2017) indicated that the findings from their study on the influences on the participation of wheelchair rugby athletes (n = 10) in disability sport lend support to this argument.

Historically, the medical model came into existence as a discursive construction that scholars have used to advance various forms of critique of how medical professionals understand having a disability and manage the conditions of disabled people (Hogan, 2019).

Critique of the medical model generally falls within three main arguments. First, the model's reliance on biophysical assumptions of normality perpetuates a normal/abnormal binary in which disabled people are viewed as defective. As a result, nondisabled people are imbued with authority and power that they can then exercise over disabled bodies (Smith & Bundon, 2018). Second, by locating disability within the body of the person, the model leaves oppressive societal attitudes and structures unchallenged (Goodley, 2012; Thomas, 2007). Lastly, the model has been criticized for negatively framing *having a disability* as a personal physical tragedy and a psychological trauma that should be overcome (Smith & Bundon, 2018). For the vast majority of people with disabilities, there is no overcoming having a disability. It is something that they will always have. Framing disability as something always in need of fixing sends a message that can dehumanize and de-normalize people with disabilities. The above criticisms have served as the foundation for researchers developing and pushing forward alternative understandings of *having a disability*.

3.1.2. Social Models of Disability

In contrast to the medical model, social models of disability are rooted in a philosophy where *having a disability* is viewed as a problem of society (Smith & Bundon, 2018). To date, multiple variations of the social model, such as the North American social model of disability (Hahn, 1985a), the Nordic social relative model of disability (Tøssebro, 2004), and the United Kingdom social model of disability (Oliver, 1990), have been proposed in the literature. What follows is a brief description of the three models in the order in which they were proposed. Next is the synthesis of the social models, which will include an explanation of the origins of the

social models and how each fits in the wider sociopolitical and historical context. To conclude this section, there will be a discussion of the support and criticism leveled at the social models.

3.1.2.1. The North American Social Model of Disability. The North American social model of disability, also referred to as the Social Minority Model (Hahn, 1985a; hereafter referred to as the North American model), defines disability as the product of institutionally based oppression of people with disability minority status (Rocco, 2005; Scotch & Schriner, 1997). The North American model espouses the view that it is the discriminatory structured social environment, which limits opportunities and fails to adjust to the needs and aspirations of disabled people, that produces *having a disability* rather than an individual's impairment (Hahn, 1986). This model emphasizes that having a disability minority status can have social consequences in the form of behaviors such as prejudice, discrimination, and alienation (Shapiro et al., 2012). The model does not make a point of distinguishing between impairment and disability (Owens, 2015). As a result, the model ignores the potential influence that impairment may have on disability and vice versa.

3.1.2.2. The Nordic Social Relative Model of Disability. The Nordic social relative model of disability (Tøssebro, 2004; hereafter referred to as the Nordic model) defines disability as "a mismatch between the person's capabilities and the functional demands of the environment" (p. 4). The Nordic model's definition is based on a relational understanding of disability (Rosqvist et al., 2018). It is in the interaction between the environment and the individual, as well as the personal factors that affect them (e.g., impairment, gender, race), that disability is produced. Tøssebro (2004) articulated three main assumptions of the Nordic model. First, disability is created by the mismatch between the individual's functioning and the demands of

the environment. Rather than having a disability being considered an individual's defining characteristic, the focus shifts to an individual's capacities and abilities. Second, disability is situational or contextual, which means that individual impairments can be more or less disabling depending on the situation. Third, disability is relative to the environment/society that an individual is in. According to Owens (2015), the Nordic model makes room for both the environment and impairment. While the environment is an important factor in the individual-environment relationship, impairment and its consequences for the individual are also recognized. In effect, impairment and disability interact with each other along a continuum (Smith & Bundon, 2018).

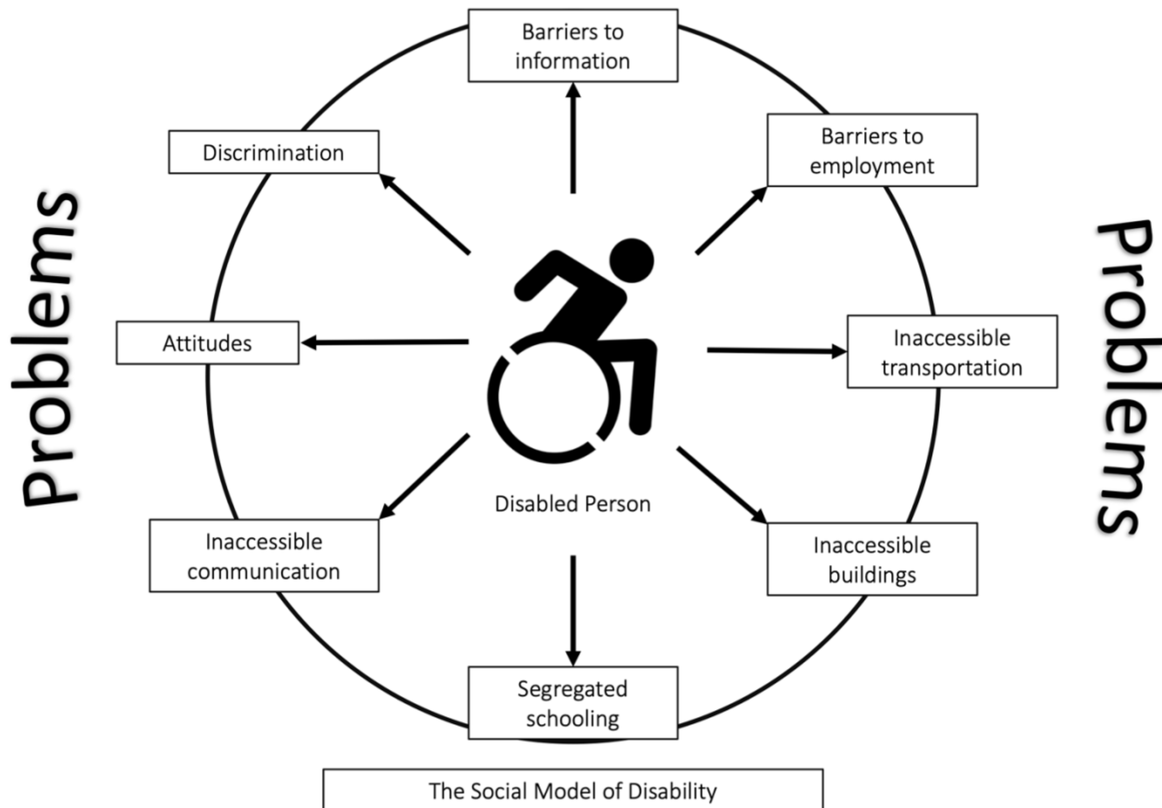
3.1.2.3. United Kingdom Social Model of Disability. The United Kingdom social model of disability (Oliver, 1990; hereafter referred to as the UK model) defines disability as "the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers" (Barnes, 1991, p. 2). The model makes the distinction between disability and impairment (Oliver, 1990). The former is a product of society and multifaceted societal oppression, and the latter is an individual, private physiological condition. The UK model asserts that *having a disability* is caused by structural and attitudinal social barriers that people with impairments encounter across situations and contexts. Under this view, it is understood that an individual's experience of having a disability depends on the society that they live in. Oliver's (1990) account analyzes how British capitalist society disables people with impairments while highlighting how oppressive social perceptions and arrangements create social exclusion. According to the UK model, the appropriate solution to

improving disabled people's lives is the removal of oppressive social barriers and the implementation of social policies that facilitate full social inclusion.

3.1.2.4. Social Models of Disability: Conceptual Synthesis of the Models. While each variation of the social model details a unique interpretation of *having a disability*, the models also share intellectual and philosophical commonalities. As illustrated in Figure 2, all of the social models presented above place the disabled person at the center of the model. The "problem" of having a disability is external to the disabled person and is represented as a variety of societal barriers that surround the person and constrict their participation in society (Darcy & Buhalis, 2011). Each variation of the social model emphasizes this issue of participation (Owens, 2015), whether that is in disabled people's daily lives or in crafting public policy. The one-directional arrows in Figure 2 serve to point at the "problem" and demonstrate the obstruction of a disabled individual's participation by the identified barriers. A key tenet of the social models is the belief that *having a disability* and disablement are socio-political constructs (Lang, 2001). Therefore, the systematic oppression, exclusion, and discrimination that having a disability brings forth is a result of the structural (i.e., inhospitable physical environment) and attitudinal (i.e., negative social attitudes) social barriers that people with disabilities encounter. From this perspective, having a disability requires changes in society to achieve emancipation (Finkelstein, 2001). Appropriate solutions to the "problems" situated in the surrounding social conditions are the removal of barriers to participation in social, political, and economic life and the provision of resources that facilitate full social inclusion.

Figure 2

The Social Model of Disability



All of the variations of the social model also share a common time period of origin, dating back to a time of civil unrest post-World War II. Countries were contending with a large population of injured war veterans, and thousands had been affected by diseases such as polio (Magno & Golomb, 2020), presenting a challenge to nations. Diverse historical, intellectual, and political positions shape the variations of the social model and create unique interpretations of *having a disability*. In the United States, minority group rights-based social theory that developed in the Civil Rights Movement against racial segregation and discrimination was subsequently applied to the oppression of disabled people (Frum, 2000), which led to the

development of the North American model. The role of government, in this view, is to protect the civil rights of disabled people to fully participate in political, economic, and social life by eliminating discrimination (Hahn, 1985b). Harlan Hahn, a disabled man, was a leading academic voice behind the development of this model. Under this model, *having a disability* is treated as a political issue that requires political action grounded in the individualization of disability (e.g., identity politics; Siebers, 2002). The origins of the Nordic model (Tøssebro, 2004) can be traced back to the late 1960s in a Norwegian White Paper that argued for an 'environmental turn' in disability policy (Stortingsmelding 88, 1966–67). In Nordic countries (e.g., Sweden, and Norway), social theory developed through the creation of high-investment welfare states and opposition to institutions (Roulstone, 2013). The Nordic model developed paternalistically through state research institutes and policy drivers. In the UK, social theory developed to emphasize the capitalist economic exclusion of disabled people in British society's reformation of the welfare state (Barnes et al., 1999; Tregaskis, 2002). The Union of Physically Impaired Against Segregation (UPIAS, 1976) and Finkelstein (1980) argued that, in the UK, disabled people are an oppressed group with shared experiences of oppression and structural barriers that may be addressed by social change and political action at the structural level (Oliver & Barnes, 2012). This laid the foundation for the UK model, which was developed by Mike Oliver (1990), a disabled man. Each of the social models have been a powerful tool used in crafting public policy associated with having a disability and developing education for students with disabilities (Anastasiou & Keller, 2011; Beckett & Campbell, 2015; Samaha, 2007; Thomas, 2004). Social models of disability have also been viewed as empowering disabled people to

recognize having a disability, not as a problem of the body or a deficit within the person, but more often as a problem created by society (Smith & Bundon, 2018).

3.1.2.5. Social Models of Disability: Synthesis of Research Evidence. Thus far, evidence in support of the social models has consistently demonstrated that having a disability due to SCI results in barriers to social participation in major life domains: lack of employment opportunities (Carpenter et al., 2007), inadequate social support (Noreau & Fougeyrollas, 2000), limited access to recreational and leisure activities (Kennedy & Rogers, 2000), and inaccessible transportation (Cox et al., 2001; Whiteneck et al., 2004). In contrast, Papadimitriou's (2008) research which explored the experience of re-embodiment and having a disability among adults with SCI in their efforts to become wheelchair users, presented results that conflict with the assumptions of the social models. Her results suggested that *having a disability* is a situated accomplishment, placing disability in relational terms.

Collectively, the social models are not without critique. First, the social models of disability have been criticized as too idealistic. It is not practically possible to remove all physical barriers from the world nor can the social environment be adjusted in a way that will positively impact all disabled people (Shakespeare, 2014). Second, the social models have been criticized for ignoring the individual subjectivities and the differences and complexities that may exist in everyday experiences of having a disability (Hughes & Paterson, 1997; Marks, 1999; Paterson & Hughes, 1999). Smith and Bundon (2018) emphasized that, by separating people's private accounts from the public issues of social exclusion, a wide variety of experiences of impairment are overlooked. Some (e.g., Shakespeare & Watson, 2001) have called the social models of

disability an outdated ideology in need of replacement, while others (e.g., Thomas, 2007) believe it needs further development.

Each of the social models also draw critique in unique ways. The North American model is criticized for reducing ableist attitudes solely to socio-institutional practices or public policy (Imrie, 1997). Critics claim that essentially defining disability by public laws and programs limits the pathway to emancipation to equal opportunity policies, among other measures, and ignores the biophysical reality of disabled people that demands a difference in the way society responds to them (Imrie, 1997). The Nordic model has been criticized for a view that is said to maintain biomedical assumptions that disabled people are categorically flawed individuals (Berg, 2004). By linking having a disability with injury and disease, this view is believed to label disabled people as incapable of performing social roles in the same way as nondisabled people (Berg, 2004). The UK model has been criticized for excluding the body (Hughes & Paterson, 1997; Thomas, 2007). By separating impairment from disability, the UK model created a dualism that treats the impaired body as purely biological, untouched by society or culture, and isolated from disabled people's embodied experiences (Hughes & Paterson, 1997). While this model de-medicalizes disability, it leaves behind the impaired body, essentially relegating it to the jurisdiction of biomedical methods and theories of interpretation. This construction of disability ignores the agency, meaning, affect, and history of bodies and the socio-cultural oppression experienced by having an impaired body during interactions with other people and the structural environment.

3.1.3. Social Relational Model of Disability

To address the dissatisfaction with the medical model and the shortcomings of the social models, Carol Thomas (1999) proposed the “rescue” and development of a social relational understanding of disability. The social-relational model of disability (SRM; Thomas, 1999, 2004, 2007) defines disability as “a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being” (Thomas, 1999, p. 60). This model builds upon the conceptualization of disability originally crafted by the UPIAS (1976), that “disability is something imposed on top of our impairments” (p. 14), to include both structural and psycho-emotional dimensions of disability. This conceptualization addresses the limitations of previous models by recognizing the direct and immediate effects of impairment and the various social restrictions that may arise at the same time (Thomas, 1999, 2014). In the SRM, Thomas (2007) proposes that the concepts of disability, disablism, and impairment are manifestations of social relationships, which are produced as people interact with social structure and social agency. She argued that, to understand *having a disability*, we must engage with social structure and social agency by devoting analyses of having a disability to “social relations and social forces that construct, produce, institutionalize, enact and perform disability and disablism” (Thomas, 2007, p. 181–182).

In the SRM, impairment is a biophysical reality that manifests as reduced physical, sensory, or mental function (see Figure 3, Point 1; Thomas, 2014). An individual’s impairment is a necessary condition to bring about various forms of social oppression that may result in disablement (Reindal, 2008). Having an impairment can directly affect how you feel (i.e.,

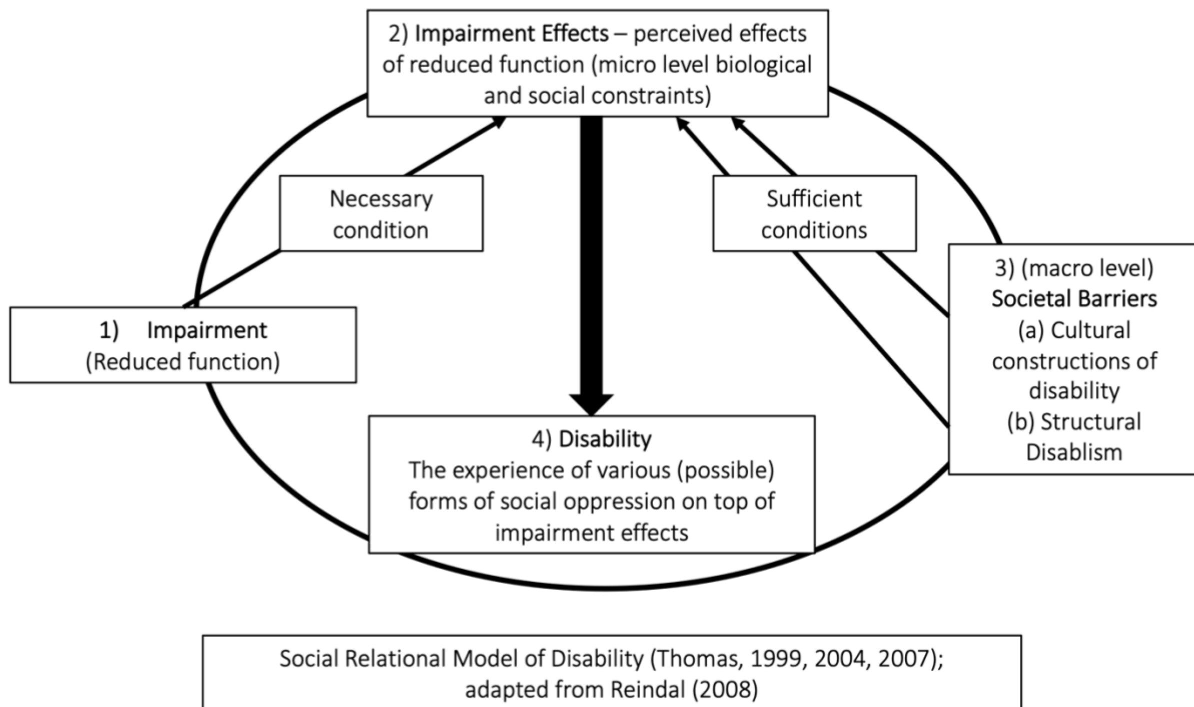
damage psycho-emotional well-being) and what you can do (i.e., restrict activities) through micro-level constraints such as chronic pain. The perceived effects of these constraints on the everyday lives of disabled people that arise directly from impairment are called impairment effects (see Figure 3, Point 2; Thomas, 2004). In the case that impairment effects are purely corporeal, disablism is not considered to have occurred. Impairment does not bring about social oppression because, in this case, it is simply the biophysical reality of having an impaired body that is affecting a person's activity or well-being (Smith & Perrier, 2014). Whether impairment and its perceived effects lead to disability is entirely dependent on the influence of macro-level social constraints (Reindal, 2008). Impairment is not in itself a sufficient condition for disability since impairment does not generate disablement unless various circumstances are satisfied (e.g., time, place, people involved; Reindal, 1998). Macro-level societal barriers that make it possible for people to experience various forms of disablism are the cultural constructions of disability and structural disablism (see Figure 3, Point 3).

The SRM extends the concept of disablism by proposing four social contexts in which disabled people can experience social oppression (i.e., structural disablism, indirect or direct psycho-emotional disablism, and internalized oppression; Reeve, 2014). First, restrictions that arise from disabling social barriers (e.g., inaccessible environment, employment discrimination) that directly affect what people can do are examples of structural disablism (Reeve, 2012). Second, restrictions that arise from negative experiences with cultural constructions of disability (e.g., interactions with negative societal attitudes and discourse) are examples of direct psycho-emotional disablism (Haslett et al., 2017). Third, restrictions that arise from negative experiences with structural disablism, such as exclusion from opportunities and

services (e.g., anger and frustration at inaccessible buildings), are examples of indirect psycho-emotional disablism. Fourth, restrictions that are self-imposed because of the acceptance and incorporation of prejudices that undermine psycho-emotional well-being are examples of internalized oppression (Reeve, 2004). The internalization of prejudices can damage confidence and self-esteem and shape thoughts and actions (e.g., avoid participation in sport; Haslett et al., 2017). The experience of having a disability depends on whether the different forms of social oppression detailed above emerge from the conditions provided by social interactions and impairment effects (see Figure 3, Point 4).

Figure 3

The Social Relational Model of Disability



The SRM establishes a unique understanding of *having a disability* as it accounts for a variety of life experiences of disabled people (Thomas, 2007). Thomas, a disabled woman,

brings an insider perspective to this model and the experience of having a disability. Smith (2013a, b) believed that, when paired with other approaches, the SRM provides useful insights into how having a disability can lead to social oppression and result in damage to one's psychosocial well-being during social interactions, regardless of the presence of structural barriers.

Thus far, only a few studies have used the SRM when examining what it means to *have a disability*; a limited number used the SRM within the domain of sport and exercise psychology (e.g., Allan et al., 2019; Haslett et al., 2017; Martin, 2013; Richardson et al., 2017; Smith, 2013a, b). In an overview of selected research on physical activity engagement by people with physical disabilities that used a social relational perspective, Martin (2013) demonstrated that, while barriers to physical activity engagement exist and can be easily classified along the lines of the medical model and social model, there are barriers that are not easily classified. He found that medical model and social model classifications are not representative of the reality that people with disabilities face. Martin called for more dialogue within the field of sport on the SRM. Smith (2013a) found evidence to support the SRM in a study of the health narratives told by men with sporting SCI (n = 17). He noted that by engaging in physical activity the participants were able to increase functionality, control, and independence, which helped them manage impairment effects and minimize the psycho-emotional damage of such effects. Smith's results also suggested that the actions of nondisabled people in social interactions with people with impairments, whether intentional or not, may damage the psycho-emotional well-being of those with impairments and, concomitantly, their sense of masculinity. Smith (2013b) demonstrated the SRM in action through the use of an ethnographic creative nonfiction

constructed from the data of men with sporting SCI (*n* = 20). The story showed that, within social relations, the impaired body can become a site for oppression, a source of discrimination, and a means of positioning the individual within, and orienting them towards, society in ways that might restrict what they can do and what they can become.

Haslett and colleagues (2017) utilized the SRM to interpret influences on participation in disability sport. They found support for the use of the SRM as a heuristic to investigate the subjective experience of having a physical disability in sport. They also found support for the conceptualization of individual and social factors as inextricably linked in their influence on sport participation. Richardson and colleagues (2017), in a study of gym experiences by people with physical disabilities (*n* = 21), also found support for the use of the SRM to interpret the subjective personal experience of having a disability and disablism in a sport and exercise context. Allen and colleagues (2019) adopted the lens of the SRM to examine how coaches shaped the experiences of athletes (*n* = 21) in disability sport. They found support for the use of the SRM in understanding disabled athletes' experiences. Through this lens, the disabled athlete's impairment became a site on which the prejudicial actions of coaches could damage athletes' emotions and negatively affect their behaviors in a way that undermined performance or motivation for continued participation.

Researchers have found the SRM to be very complicated (e.g., Smith, 2013a, b). Some believe the introduction of impairment effects over-complicates our understanding of having a disability (e.g., Shakespeare & Watson, 2010). Others have found it hard to parse the different aspects of the model. Owens and colleagues (2014) found it difficult to ascertain where the boundaries lay between disability and impairment. Haslett and colleagues (2017) described the

analytical task of separating restrictions in society from restrictions imposed upon by society as particularly challenging. They also argued that the SRM, while foregrounding the experience of having a disability, gives greater attention to the psychologically damaging effects of negative interactions over the psychological benefits of positive interactions. This may make it more difficult to provide a balanced report of the effects of having a disability.

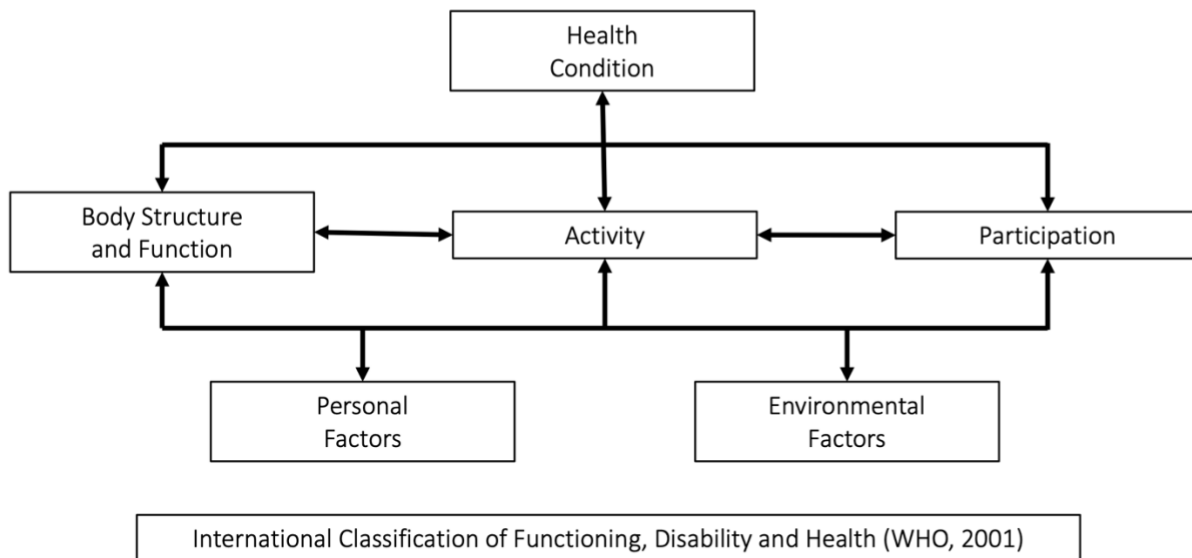
3.1.4. International Classification of Functioning, Disability, and Health

Another model used to explain *having a disability* is the World Health Organization's (WHO) International Classification of Functioning, Disability, and Health (ICF; 2001). In the ICF, *having a disability* is understood to be a state of decreased functioning experienced as impairment, activity limitation, or participation restriction that comes about due to negative aspects of the dynamic interaction between an individual's health condition and contextual factors (Leonardi et al., 2006). The ICF places disability on a continuum with health, on which having a disability is understood as a health experience that depends on context (Kostanjsek, 2011). The model, as portrayed in Figure 4, identifies three levels of factors involved in providing a descriptive profile of an individual's functioning and disability. At the first level of the model is an individual's health condition, i.e., the presence or absence of diseases, disorders, and injuries that may impact functioning (Kostanjsek, 2011). The second level of the model illustrates the cyclical, bidirectional relationship between the three domains of functioning: (a) body functions and structures, (b) activities, and (c) participation in life roles. These three domains represent the three levels of human functioning classified by the ICF (WHO, 2002). Body functions and structures represent functioning at the level of the body. Activities represent functioning at the level of the whole person. Participation in life roles

represents functioning of the whole person in context. Dysfunction at one or more of the levels of functioning (i.e., impairment, activity limitations, and participation restrictions) results in disability. The ICF assumes a bidirectional relationship between the three domains of functioning outlined above and the factors that make up the context for functioning, including health conditions, personal factors (e.g., sociodemographic considerations), and environmental factors which include both physical (e.g., built environment) and social factors (e.g., social attitudes). At the third level of the model, both personal and environmental factors (whether they are facilitators or barriers) influence how having a disability is experienced (Üstün, 2012).

Figure 4

The International Classification of Functioning, Disability, and Health



Published in 2001 as the final revision of the International Classification of Impairments, Disabilities, and Handicaps, the ICF was developed as a framework for describing and organizing information on functioning and disability associated with health conditions (WHO, 2002). It was designed in a move away from using pathology-focused resources to understand disabled

people, such as the Diagnostic and Statistical Manual of Mental Disorders, which focuses nearly entirely on an individual's deficits (Marini et al., 2011). The ICF is a biopsychosocial model that synthesizes aspects of the medical and social models (WHO, 2002). It provides an integration of biological, individual, and social perspectives on health and disability. The model is founded on a universal approach (Kostanjsek, 2011). It assumes that all people are at risk of disablement to various extents irrespective of health condition and the time in their lives.

There is support for the use of the ICF as a framework to understand *having a disability*. The ICF has been described by Cerniauskaite and colleagues (2011) as the most comprehensive classification system of disability. They state that the ICF makes it possible to describe having a disability at multiple levels and account for the environmental factors involved in this experience. The model has been used as a framework to review factors related to the participation of children with spina bifida (Bakanienė et al., 2018), interpersonal interactions and relationships after SCI (Amsters et al., 2016), social and community participation after SCI (Barclay et al., 2015), the health and functioning experience of adults with chronic conditions (Alford et al., 2014), and leisure time physical activity participation of the physically disabled (Martin Ginis et al., 2016). Bakanienė and colleagues (2018) found that all environmental domains in the ICF had a direct influence on the participation of children with spina bifida.

Amsters and colleagues (2016) found support for the use of the ICF as a framework for organizing and interpreting factors that influence interpersonal interactions and relationships after SCI. They also found that the experience of interpersonal interactions and relationships post-SCI was facilitated by partner and social support, reciprocity in relationships, and presenting oneself positively, and impeded by physical environmental barriers, real and

perceived social biases, and poor self-image. Barclay and colleagues (2015) found adequate personal care assistance, appropriate social support, adequate specialized equipment, and appropriate occupational therapy input facilitated social and community participation following SCI, whereas problems with transport, inaccessibility of the natural and built environment, issues with healthcare services and rehabilitation providers, and pain were barriers.

In a review of the literature that used the ICF to elicit the personal narrative of the health and functioning experience of people with chronic conditions, Alford and colleagues (2014) found the ICF provides a comprehensive analysis of experiences and needs from the person's perspective. Martin Ginis and colleagues (2016), in a review of factors related to leisure time physical activity participation among people with SCI, found evidence to support Fekete and Rauch's (2012) findings that the ICF is unable to incorporate all factors related to sport and exercise within the ICF. Wilhite and Shank (2009) used the ICF to frame the personal narratives of disability sport participants (n = 12) who chose to maintain their health through sport. Their findings indicated that the sport participation of those who have a disability led to enhanced functional capacity, health promotion, relationship development, increased optimism, and inclusion in meaningful life activities and roles. Wilhite and Shank also found that the lived experiences of the disabled participants suggested an intersection of ICF domains and components that goes beyond the implication of discrete components.

There are numerous critiques of the ICF. First, critics point out that health conditions do not arise in a vacuum (Mitra & Shakespeare, 2019). The ICF does not directly connect health conditions with environmental and personal factors. As such, the model ignores the fact that health conditions influence and are influenced by an array of contextual factors (Mitra &

Shakespeare, 2019). Second, critics have found fault with the model for founding the basis of the system upon a medical view of health conditions, disorders, and diseases (Andersson, 2006; Hammell, 2004). As a consequence, the model remains rooted in structural functionalism (Hurst, 2003), which means it views disabled people as having something wrong with them that needs to be fixed rather than addressing the social, cultural, and economic forces at work. Third, the complexity of the ICF has led some to find it difficult to apply in daily practice (Jacob, 2013; Üstün et al., 2004). Mitra and Shakespeare (2019) point out that the model is normative as it requires the selection of relevant dimensions that do not provide an exhaustive account of the lived experience of disability. Fourth, there are theoretical complications between the core concepts of activity and participation, and performance and capacity, which have led to issues in coming to a consensus regarding the distinction between these concepts (Jelsma, 2009). Mitra and Shakespeare (2019) also point out how limited the ICF is in assessing human lives and the impact of health conditions when activities and participations are all that is considered. The ICF does not create a place for the psychological world of the disabled individual. While this model identifies features of the physical, social, and attitudinal world that may act as barriers or facilitators for individuals (Üstün, 2012), it fails to account for the individual's thoughts and feelings. Only a mechanical understanding of mental function is included in the body function domain.

3.1.5. Synthesis of Research on Having a Disability

The models above shed light on the complexity of conceptualizing what it means to *have a disability*. Based on the existing models and empirical evidence, it is apparent that each of the models has a clear yet unique way of defining *having a disability*. What is common is that

each model defines disability in a negative manner (e.g., a problem, failure, mismatch, loss, imposition; see Table 1). Using these terms, *having a disability* is understood to be fundamentally negative, and it is the negative definitions that shape the way the models are conceptualized.

Table 1

Models of Disability: Definitions

Model	Definitions
Medical Model of Disability	"a medical problem that resides in the individual. It is a defect in or failure of a bodily system and as such is inherently abnormal and pathological" (Olkin, 1999, p. 26)
North American Social Model of Disability	The product of institutionally based oppression of people with disability minority status (Rocco, 2005; Scotch & Schriner, 1997)
Nordic Social Relative Model of Disability	"a mismatch between the person's capabilities and the functional demands of the environment" (Tøssebro, 2004, p. 4)
UK Social Model of Disability	"the loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers" (Barnes, 1991, p. 2)
Social Relational Model of Disability	"a form of social oppression involving the social imposition of restrictions of activity on people with impairments and the socially engendered undermining of their psycho-emotional well-being" (Thomas, 1999, p. 60)
International Classification of Functioning, Disability, and Health	A state of decreased functioning experienced as impairment, activity limitation, or participation restriction that comes about due to negative aspects of the dynamic interaction between an individual's health condition and contextual factors (Leonardi et al., 2006)

As a consequence, the models fail to capture the positive aspects of disability. The models essentially ignore the value of having a disability or the psychological benefits people might experience (e.g., positive meaning and feelings, "silver linings"; Cole, 2004; Dunn, 1994; Tran et al., 2011; Wright, 1983). This is inherently problematic, as the domination of the models

and their negative connotations in both academic and general discourse may influence how disabled people see themselves and their disabilities. This may also affect the way the experiences of disabled people are received and interpreted by researchers and practitioners.

The shared negative connotations of having a disability across the models are not surprising, as each model exists largely as a rebuttal, extension, or combination of previous models. The medical model assumes that disability is a problem within the person's body, which leaves oppressive societal attitudes and structures unchallenged. The social models were a response to the medical model. These models share the assumption that disability is a problem created by a variety of societal barriers that constrict a disabled person and their participation in society. Essentially, social model theorists accepted that having a disability is a problem, but they disagreed on where it was produced. This meant that the framing of disability as a "problem" went uninterrogated. The medical model and social models are representations of opposite paradigms, thus creating a black-and-white understanding of *having a disability*. The trouble with framing understandings of disability as one or the other is that it ignores important aspects of having a disability, such as individual subjective experiences of impairment and disability. Illustrating the failure of the medical model and social models, research has shown that both individual and social factors influence a person's experience of having a disability (Barclay et al., 2015). These factors have also been found to be inextricably linked (Haslett et al., 2017). Additionally, Martin (2013) demonstrated that neither the medical model nor the social models can adequately classify the barriers that disabled people experience.

The SRM was an extension or “rescue” of relational thinking left behind in early social model theorizing (i.e., UPIAS, 1976). It is one of the most comprehensive models to date to explain *having a disability*. It incorporates the lived experience of the body, recognizing the direct effect of impairment (Thomas, 1999). It also includes the psycho-emotional impact of disablism, proposing four distinct contexts in which disablism can occur. The SRM does address important issues with the social models. It is unique in that it incorporates the subjective experience of having a disability while also acknowledging the body is simultaneously biological, social, cultural, and agentic (Smith & Bundon, 2018). While this model, acting as an extension of the social models, moves the conversation about having a disability forward, it is ultimately theoretically flawed as it accepts the social models’ negative framing that *having a disability* is a problem.

The ICF is the WHO’s attempt at a comprehensive model of disability, one that merges the medical model and social models. This interactionist account of disability assumes that *having a disability* is produced by the interaction between biological, personal, and environmental factors. While this model did create a new conceptualization of *having a disability*, it relied on the assumptions of the medical and social models by emphasizing the problem in the body and the problem in the environment, essentially highlighting an interaction between negative aspects of having a disability. While Alford and colleagues (2014) found support for the ICF as a comprehensive analysis tool to investigate the experiences and needs from the disabled person’s perspective, the ICF fails to consider agency (Mitra & Shakespeare, 2019) and the individual’s psychological world. Due to the greater attention the SRM gives to the variety of life experiences of disabled people as well as the influence of their inner

psychological world, it has been shown to be the most comprehensive model discussed. There is research evidence that demonstrates the SRM's conceptualization of *having a disability* can be used as a heuristic to investigate the subjective experiences (Haslett et al., 2017; Richardson et al., 2017) and personal narratives of having a disability (Smith, 2013a, b).

Aside from the medical model from which interpretations of *having a disability* originally spawned, the social models, SRM, and ICF are all founded on a social understanding of *having a disability*. This means that *having a disability* is understood to be, at least in part, a problem created by social factors in the social environment. Another commonality is that the social models, SRM, and ICF all focus on participation. These models assume that having a disability can have consequences for one's participation in society. Also common among the models (i.e., the ICF, SRM, Nordic model, UK model) is the assumption that *having a disability* depends on context. What may produce disability in one time, place, or group of people may not in another.

None of the models are comprehensive. Aside from a total ignorance of the positive aspects of having a disability, there are other important gaps in each model. Of note, the models fail to account for a disabled person's autonomy. There is talk of agency in the SRM but not of an autonomous agent. Throughout this discussion of disability models, there is no mention of the role that one's motives play in the experience of having a disability. This is important as the individual is regarded as mostly passive; having a disability is something that happens *to* you. The models represent a series of developments that are inherently harmful to our thinking about *having a disability*. While some of the models discussed may not be fatally flawed, they must be paired with theory that emphasizes autonomy and a positive or balanced understanding of *having a disability*.

The various explanations and understandings of *having a disability* provided by the models in this section draw the attention of disabled and nondisabled researchers and practitioners alike to particular aspects of having a disability, which then shapes the psychological, social, political, and economic responses and outcomes associated with disability (Dembo, 1982; Hahn, 1993; Zola, 1993). Smith and Sparkes (2004) demonstrate that stories linked with particular disability model discourse can play an important role in shaping how disabled individuals interpret their experience of having a disability and the experiences of others.

Research concerning what it means to *have a disability* is limited. Few studies in the domain of sport and exercise psychology research have engaged with models of disability. Less have utilized a disability model to examine *having a disability* with people with acquired SCI (Bryden, 2020; Papadimitriou, 2008; Smith, 2013a, b). Among men athletes who have acquired a SCI, there have been two studies that have utilized a particular model as a framework for understanding the experience of having a disability after transitioning out of sport (i.e., SRM; Smith, 2013a, b). In the literature, there has been *no* research utilizing a disability model to explore *having a disability* with women athletes who have acquired a SCI. This represents a gap in our understanding of what it means to *have a disability*, particularly as it relates to the psychosocial adaptation experience of women athletes after SCI. While there is research to support an interactionist (e.g., Amsters et al., 2016; Bakanienė et al., 2018; Barclay et al., 2015) and relational perspective (e.g., Papadimitriou, 2008; Smith, 2013a, b) of *having a disability*, there is limited research that considers the individual's subjective experience (Haslett et al., 2017; Richardson et al., 2017). Collectively, the key problems with the current

conceptualizations of *having a disability* are that they are rooted in a negative understanding of disability that lacks consideration for the disabled person's autonomy and subjective experience, particularly the experiences of women athletes who have acquired a SCI.

3.2. Being (Disabled)

To be white, a woman, disabled, cisgender, these are a set of characteristics that distinguish a person from others. Each of these characteristics may signify an aspect of one's identity. Identity is "defined by (a) a set of physical, psychological, and interpersonal characteristics that is not wholly shared with any other person and (b) a range of affiliations (e.g., ethnicity) and social roles" (American Psychological Association, n.d.). It is the way an individual defines, locates, and differentiates I from others (see Hewitt, 1992). Identity is not a fixed attribute, as it is a relational phenomenon that develops through a process in which individuals interpret themselves in a certain way and then are recognized as such depending on the situation (Gee, 2001). Mead (1934) recognized that identity is the product of an interplay between the self and the environment.

Every person has multiple intertwined identities (Scheuringer, 2016), some more salient than others depending on the situation (Stryker & Serpe, 1982, 1994). Given the definition of identity outlined above, *being disabled* is likely to be, or become part of, one's identity. According to Dunn and Burcaw (2013), disability identity is a "sense of self that includes one's disability and feelings of connection to, or solidarity with, the disability community" (p. 148). This definition indicates that disability identity is comprised of both personal and relational concepts. This means that, to understand what it means to *be disabled*, one must consider the internal and external factors involved. Research supports the conceptualization of disability

identity as being largely influenced by a person's beliefs about disability and elements of the social environment in which the person functions (Darling, 2003; Dorozenko et al., 2015; Gagliano, 2021; Kinavey, 2006; Zhang & Haller, 2013). Also, research indicates that disability identity is important to the psychosocial health of people with disabilities (Bogart, 2014, 2015; Dunn & Burcaw, 2013; Gill, 1997). A healthy disability identity acts as a protective factor against ableism (Mpofu & Harley, 2006) and has been theorized as a factor that facilitates positive adaptation to disability (Dunn & Burcaw, 2013).

Identity also represents one aspect of the self (McAdams, 1995). A fundamental consequence of serious chronic illnesses such as SCI is the loss of self and, as such, the disruption of one's identity (Charmaz, 1983). It is known that how a person understands themself is intertwined with their body (Gadow, 1982), and when SCI undermines the unity between the body and the self it may force changes to one's identity (Charmaz, 1995). To accommodate the sudden changes to the body and reunify the body and the self, individuals with acquired disabilities must renegotiate their identities and reintegrate their sense of self (See Charmaz, 1995). Who are they after their body has changed? How they choose to define themself in association with disability is a major identity dilemma (Charmaz, 1994). Individuals with acquired disabilities must reconcile the aspects of their identity they have lost, what has changed, and what remains (Adler et al., 2019); and then decide whether to integrate disability into their identity. The product of this redefinition of one's identity is the creation of an identity based on one's new life situation (Corbin & Strauss, 1987). In the sections that follow, several prominent models that aim to explain what it means to *be disabled* will be introduced.

3.2.1. Disability Identity Development Models

The literature on disability identity has largely focused on disability identity development (Forber-Pratt et al., 2017). Many prominent models of disability identity attend to the process of identity development (e.g., stages, statuses), not necessarily the factors that constitute what it means to *be disabled*. In the sections that follow, several models that aim to explain disability identity and how it develops will be introduced: (a) Gill's disability identity development model (1997); (b) Gibson's disability identity development model (2006); (c) Caldwell's disability identity thematic model (2011); and (d) the model of social and psychosocial disability identity development (Forber-Pratt & Zape, 2017).

3.2.1.1. Gill's Disability Identity Development Model. Carol Gill (1997) was among the first to research disability identity. In her seminal work, she introduced a stage model of disability identity development focused on achieving psychological integration, a sense of wholeness complete with disability, on both individual and group levels. Drawing from both personal experience as a person with a disability and discussions with her disabled clients about who they are and where they belong, Gill, a practicing clinical developmental psychologist, identified four different types of integration in the development of disability identity. These four types of integration include (a) coming to feel we belong, (b) coming home, (c) coming together, and (d) coming out. To understand what it means to *be disabled*, the different types of integration represent aspects of being disabled, of being whole with disability, at different stages of disability identity development.

The first type of integration is "coming to feel we belong," representing integration into society (Gill, 1997). At this stage, being disabled involves asserting one's right to equal

consideration as compared to nondisabled people and placing the blame for restrictions on external factors. The second type of integration is "coming home," which represents integration with the disability community (Gill, 1997). At this stage, being disabled involves experiencing feeling states such as joy, acceptance, and comfort in interactions and relationships with disabled peers rather than feelings of shame or embarrassment. The third type of integration is "coming together," which represents the internal integration of one's sameness and differentness (Gill, 1997). This stage involves affirming the disability experience as a positive feature of disabled people's identities and rejecting the cultural values that reject their differentness. It is here when being disabled would mean accepting one's disability. Finally, the fourth type of integration is "coming out," which represents the integration of how one feels with how they present themselves (Gill, 1997). At this stage, being disabled means aligning one's sense of self with their idealized self-image and making an effort to return to mainstream society without the need to pass or hide one's disability.

Gill's (1997) four types of integration indicate that individuals move through stages of identity development towards a disability identity that supports greater self-definition, interpersonal comfort, social integration, and authentic personal expression (Gagliano, 2021). By doing so, this model presumes that disability identity is malleable. While this model describes stages, it does not imply a direct temporal relationship that one particular stage must be passed through before transitioning to the next one (Gill, 1997). A strength of this model is the author itself. Gill self-identifies as a person with a disability and she has a connection to the disability community. As such, her model was developed using her personal experience with disability as well as other disabled people's accounts. Gill's disability identity development

model was the first to be rooted purely in a social model perspective (Gagliano, 2021). The model is also the first to incorporate group identity as a component of disability identity. The inclusion of group identity suggests that one's goal is to develop a disability identity in relation to others rather than separating oneself from others. The model is structured in a way that appreciates diverse experiences of disability (e.g., congenital, acquired, chronic illness). It supports the examination of disability identity development across many disability groups.

There is limited research to support this model. Gagliano (2021) examined the first type of disability integration in the model (i.e., coming to feel we belong) in a sample of people with congenital blindness (n = 8). She argued that her study findings align well with the first disability integration type, supporting the validity and usefulness of the first integration type. Her study left the remaining three integration types unexamined. Gill's model, in its entirety, as well as the remaining three types, still need to be thoroughly tested as no other studies have been found to test or support Gill's model (Gagliano, 2021). Given the paucity of research that has explored *being disabled* with this model, there is limited evidence of its applicability to disabled populations.

Unsurprisingly, given the lack of empirical evidence, this model is criticized for being theoretical in nature (Forber-Pratt & Zape, 2017). Ostrander (2008) criticized the model for its singular focus on one aspect of identity – disability. The model ignores other aspects of identity (e.g., ethnicity, religion, sexuality) that may contribute to identity development and cause tension with disability identity. As Gibson (2006) states, many individuals view being disabled as only a part of who they are. It does not define them as a person. As such, the salience of disability identity may play an important role in what it means to *be disabled*. McNeely (2013)

also criticized the model, asserting that disabled individuals may not move through the stages in a linear manner. This means that individuals may not progress through stages in a set order. He also argued that disabled individuals might not be finished integrating disability into their identity at the final stage (McNeely, 2013). He suggests that there may be aspects of disability identity that develop beyond the final type described. His criticism calls into question the existence of a final, self-actualized state of disability identity. It must be highlighted that the focus of this model is on explaining how one's disability identity develops, not necessarily what it means to *be disabled*. Therefore, there is a lack of consideration for what domains may be included in a coherent disability identity, or how being disabled may mean something different to different people.

3.2.1.2. Gibson's Disability Identity Development Model. Gibson (2006) introduced another stage model of disability identity development. Directed particularly toward those with congenital and early-onset disabilities, Gibson's model includes three stages: (a) passive awareness, (b) realization, and (c) acceptance. The first stage is "passive awareness," which represents the individual's inability to recognize their disability (Gibson, 2006). The disabled person lacks role models, knowledge of disabilities, or support from others with disabilities. For individuals at this stage, they have often been taught to deny social aspects of disability. Being disabled means avoiding attention that is particularly focused on their disability and interactions with other individuals with disabilities. It sets the scene for an individual with a largely negative relationship with disability. The second stage is "realization," which represents the individual trying to reconcile their relationship with society (Gibson, 2006). The individual begins to acknowledge their disability. In this stage, being disabled may mean experiencing self-

hate, anger, and/or concern regarding the perceptions others have of them because of their disability. This typically happens when an individual encounters a significant experience. Being disabled, at this stage, means individuals may attempt to overcompensate and prove others wrong about their abilities. The third stage is “acceptance,” which represents the individual viewing themselves as equally relevant and valuable as others without disability, embracing a disability identity, and taking pride in their group membership. They have come to understand and accept their differences and positively integrate into the nondisabled world. For individuals at this stage, being disabled means they have bonded with others with disabilities through frequent interaction and may consider themselves disability advocates or activists.

Gibson’s (2006) model acknowledges the fluidity of individuals’ identities and emphasizes the potential for backward movement through the stages of identity development. Individuals who have moved to “acceptance” may move back to “realization” if the individual encounters negative experiences (disability-specific adversity) and stereotypes. The model emphasizes that disability identity formation is a process that occurs and continues across the lifespan (Gagliano, 2021). Gibson’s model, like Gill’s (1997), is based on two decades of clinical experience working with clients with disabilities. Gibson, who has cerebral palsy, much like Gill, brought her personal experience with disability to the development of this model. Gibson developed this model as a tool for practitioners to promote multicultural sensitivity and help practitioners understand the possible struggles and perceptions of people with disabilities.

Gibson’s (2006) model also has limited empirical support. In 2018, Gibson and colleagues developed the Gibson Disability Identity Development Scale based on Gibson’s (2006) model. In the first and only study to use Gibson’s model, they used the scale to

determine the levels of disability identity development of individuals with visual disabilities. The scale, which contains 12 statements representing the three stages of the model, was found to be a reliable tool for practitioners to use across a variety of services with those who have low vision or are blind. With a Cronbach's coefficient alpha of .73, they found the attributes were appropriately measured by the scale items. Their findings indicated the majority of their participants had moved into the acceptance stage. They viewed themselves as equal to their peers, affirmed their disability identity, had friends with disabilities, and took pride In their group membership. While Gibson and colleagues (2018) do provide support for this model, the research evidence provides limited applicability to a single disability group (i.e., low vision, blind). There is a lack of support for the validity and usefulness of this model for exploring *being disabled* across a wide spectrum of disability groups.

Gibson's model has also been criticized for being theoretical in nature (Forber-Pratt & Zape, 2017). Forber-Pratt and Zape (2017) identified two issues with the model. First, the use of acceptance as the final stage neglects the possibility that identity development can continue after one comes to terms with their disability. Second, the three stages of identity formation are highly individualistic, ignoring the external aspects of identity. As with Gill's (1997) model, the focus is on disability identity development, not necessarily what it means to *be disabled*. There is a lack of consideration for the domains included in a coherent disability identity or what being disabled may mean to different people.

3.2.1.3. Caldwell's Disability Identity Thematic Model. Caldwell (2011) created a thematic model of disability identity development from the qualitative study of (n = 13) individuals with disabilities who were leaders in the self-advocacy movement. This model is the

first published model of disability identity developed from empirical study. Due to the makeup of those included in the study, the model is directed particularly toward those with intellectual and developmental disabilities. Using a grounded theory approach (Strauss & Corbin, 1990), Caldwell constructed five disability identity themes: (a) resistance, claiming personhood and voice; (b) connection with the disability community; (c) reclaiming disability and personal transformation; (d) interconnection with broader disability rights movement; and (e) bond with social justice and interdependency.

The first theme of Caldwell's (2011) model is "resistance – claiming personhood and voice," which is represented by initial resistance to disability due to the realization of difference associated with negative social experiences such as segregation, exclusion, and bullying. Individuals in this theme may express feelings of shame from being disabled as a result of societal messages that devalue difference. Some individuals may choose to deny or even hide their disability. The first step in disability identity development involves questioning the societal devaluation of difference and claiming personhood. This means finding a voice through acts as simple as saying one's name in a meeting or talking among friends. The second theme is "connection with disability community," which is represented by the development of relationships with other disabled people, a sense of community, and a deeper understanding of the shared experience of disability (Caldwell, 2011). Individuals in this theme may experience an "a ha!" moment in which they realize a connection or bond with others. The third theme is "reclaiming disability and personal transformation," which Is represented by disabled individuals personally reclaiming disability from socially constructed and stigmatized labels. For individuals situated in this theme, being disabled means being okay with difference, embracing

difference, and integrating it into a positive self-concept. Individuals may experience a sense of pride and affirm cultural beliefs outside the mainstream derived from the disability experience. Next, the fourth theme is “interconnection with the broader disability rights movement,” which means working with the disability rights community on legislative issues and having a broader, collective disability experience. Individuals in this theme may experience a disconnect from the broader disability community due to stigmatized labels. Challenging the social construction of impairment through embodied resistance to certain labels is central to their lives. Caldwell’s final theme is “bond with social justice and interdependency,” which illustrates being disabled as accepting interdependency and bonding with the greater cause for social justice among multiple marginalized communities. Individuals in this theme express a strong bond with other minority groups through a connection with their struggles.

Caldwell’s (2011) model is rooted in a social model perspective. His model advances the application of the social model to individuals with intellectual disabilities. The model emphasizes the connection with the disability community as a fundamental aspect of disability identity development, bringing attention to the benefits of shared experiences of disability in the formation of self-concept. To date, there has been no published research to test or confirm the validity of this model, nor has there been a single study to use this model to explore what it means to *be disabled*.

Criticism of this model has highlighted the fact that the participants (i.e., disability leaders in the self-advocacy movement) included in Caldwell’s study represent a fraction of disabled people who have the capacity, ability, and desire to engage with the disability community, particularly in a political sense (Gagliano, 2021). As such, this model may not be

useful for explaining what *being disabled* means to a majority of people with disabilities. Additionally, the themes included in this model are not well defined. It is difficult to identify what constitutes being disabled in each theme. This makes the model difficult to use and test. As with the models that came before it (Gibson, 2006; Gill, 1997), this model focuses on disability identity development rather than what it means to *be disabled*. It does not consider the domains included in a coherent disability identity, nor what being disabled means to different people.

3.2.1.4. Forber-Pratt and Zape's Model of Social and Psychosocial Disability Identity Development. Forber-Pratt and Zape (2017) developed the model of social and psychosocial disability identity development, which aims to explain the disability identity development of college students with disabilities who represent a generation of people who grew up with disability rights legislation in place. Founded in Forber-Pratt and Aragon's (2013) preliminary work with college students (*n* = 4) with physical disabilities and empirical evidence from Forber-Pratt and Zape's (2017) qualitative interviews with an expanded participant pool of young college students with disabilities (*n* = 17), this model conceptualizes disability identity development using developmental statuses. Forber-Pratt and Aragon's (2013) preliminary analyses of the working model informed decisions to expand the participant sample and change the terminology of model components to statuses rather than stages, as their findings indicated that participants moved fluidly, forward and backward, among model components. Forber-Pratt and Zape's (2017) model consists of four disability identity developmental statuses: (a) acceptance, (b) relationship, (c) adoption, and (d) engagement.

The first status is “acceptance,” which involves the disabled individual and those close to them acknowledging and embracing the disability. This status includes aspects of frustration. For individuals with this status, to be disabled is to accept that they are disabled and have others close to them accept it as well. The second status is “relationship,” which involves the disabled person constructing a network of other disabled people, particularly those with similar disabilities. For individuals with this status, to be disabled means forming relationships to help them learn the ways of the community. They may derive a sense of comfort from the discussion of health-related and disability-related issues in their relationships. While some report an instant connection, others may feel they need to warm up to relationships with other disabled people. The third status is “adoption,” which involves “trying things on for size.” For disabled individuals with this status, being disabled is about testing out and deciding on adopting core values of disability culture and what they wish to incorporate into their own identity and their own lives. Forber-Pratt and Zape (2017) suggest this status serves as an interim between simply meeting with other disabled people and engaging with the community. The fourth status is “engagement,” which is represented by identity synthesis. In this status, being disabled is about the disabled individual embracing their disability and immersing themselves in disability culture. This status is also about giving back to the disability community by becoming a role model and helping others who are learning the ways of the community.

This model, much like the models described above, was developed by someone who self-identifies as a person with a disability. Anjali Forber-Pratt, a two-time Paralympian, brought her personal experience with disability to model development. According to Forber-Pratt and Zape (2017), this model suggests that individuals may be in more than one status at once. That

means that one particular status does not need to be passed through before transitioning to the next one. The model also suggests that disability identity is multidimensional, as the outlined statuses of disability identity development have important internal and external components (Forber-Pratt & Zape, 2017). Each status contains some internal and external aspects of disability identity development. This is evidenced by the influence of both the internalization of disability community values and the outward contribution and engagement with the community. In addition, this model emphasizes the importance of engagement with others with disabilities to integrate disability into the self-concept and the significance of becoming a role model and mentor for others (Gagliano, 2021).

Partial support for this model has been found through empirical research. Adler and colleagues (2019), in a study of identity integration with adults with acquired physical disabilities (*n* = 13), found support for the acceptance status as an important component in the "service" of disability identity development. Forber-Pratt and colleagues (2020) also found partial support for this model through an initial factor exploration of Disability Identity Development Scale items with adults with visible and/or hidden disabilities (*n* = 566) across several disability groups (i.e., physical, intellectual, learning, mental illness). The authors made use of the model developed by Forber-Pratt and Zape (2017) as well as evidence from Forber-Pratt and Aragon (2013) as a guide to item generation for the pilot Disability Identity Development Scale (DIDS). Using explanatory factor analysis (EFA; Fabrigar et al., 1999), Forber-Pratt and colleagues (2020) retained four factors that represent vital components to one's disability identity development: (a) internal beliefs about own disability and the disability community, (b) anger and frustration with disability experiences, (c) adoption of disability

community values, and (d) contribution to the disability community. They determined that the four factors of disability identity map “fairly” well onto the statuses created in Forber-Pratt and Zape’s (2017) model. The first factor, “internal beliefs,” and the second factor, “frustration,” appeared to represent aspects of the acceptance and relationship statuses. The third factor, “adoption of values,” was shown to relate to the adoption status, and the fourth factor, “contributions,” was shown to relate to the engagement status. The few studies to explore this model and the limited support provided by research evidence indicate that disability identity, as well as disability identity development, requires further study.

Forber-Pratt and Zape’s (2017) model has also drawn criticism. While Forber-Pratt and colleagues (2020) do lend partial support to the four statuses outlined by Forber-Pratt and Zape (2017), the four factors that they (2020) constructed through EFA for the DIDS do not directly align with the statuses of the Forber-Pratt and Zape (2017) model. This suggests that the model does not accurately capture all of the factors involved in disability identity development, nor do the statuses adequately portray the process of identity development. Additionally, in a comprehensive analysis of the DIDS on a sample of adults with disabilities (n = 1,126), Forber-Pratt and colleagues (2022) did not find sufficient evidence to support the four-factor structure of disability identity assembled by Forber-Pratt and colleagues (2020). Only a single, general factor of disability identity was supported. Their findings suggest that the four factors constructed by Forber-Pratt and colleagues (2020) lack validity and, as such, further diminish the support that Forber-Pratt and colleagues (2020) claim to provide to the components of Forber-Pratt and Zape’s (2017) model. In addition, this model does not truly consider what it means to *be disabled*; rather, similar to previous models (Caldwell, 2011; Gibson, 2006; Gill,

1997), it focuses on the components involved in disability identity development. Without consideration for what constitutes a coherent disability identity, it may be difficult to grasp all of the factors involved in disability identity development.

3.2.2. Disability Identity Models

While there are numerous disability identity development models, there are very few published models of what constitutes the disability identity construct itself. In the sections that follow, two models that aim to explain what it means to *be disabled* will be introduced: (a) Putnam's political disability identity model (2005) and (b) Dunn and Burcaw's narrative accounts of disability identity (2013).

3.2.2.1. Putnam's Political Disability Identity Model. Putnam (2005) published a theoretically-based domain model of *political* disability identity. This model conceptualizes political disability identity as the attitudes and beliefs that connect people with disabilities for the purpose of political activism. This model was developed to better understand why or why not people with disabilities support or involve themselves in disability rights issues. Putnam, drawing from a review of the literature covering the history of disability rights, the lived experience of disability, and the forces that shape the disability experience, outlined six primary domains of political disability identity: (a) self-worth, (b) pride, (c) discrimination, (d) common cause, (e) policy alternatives, and (f) engagement in political action.

The first three domains are person-centered and internal (Putnam, 2005). The first domain is "self-worth," which represents a disabled person having an opinion of themselves as being of equal value and worth as a nondisabled person. This domain involves three sub-domains involving the beliefs that disabled people (a) have the same worth as nondisabled

people, (b) can contribute productively to society, and (c) are undervalued in society. The second domain is “pride,” which represents a disabled person being proud of who they are. This domain of being disabled involves the disabled person acknowledging their status as being different from others in a way that values impairment as normative variation in human diversity. Putnam identified four sub-domains of pride: (a) claiming disability by acknowledging themself as a person with an impairment who experiences disability; (b) believing disability and impairment are not unusual, but rather a common human condition; (c) believing impairment is not inherently negative but can become so in certain contexts; and (d) recognizing being disabled as engendering membership in a cultural minority group. The third domain is “discrimination,” which represents the belief that disabled people are frequently discriminated against by other members of society based on stereotypes associated with impairment and disability. This domain has three sub-domains involving the beliefs that (a) people with disabilities are negatively stereotyped, (b) disabled people are typically treated differently in comparison with nondisabled people, and (c) discrimination leads to inequality of opportunity and disparity in access to resources. The first three domains represent the psycho-emotional aspects of political disability identity, highlighting the rejection of negative views of disability and embracing not only one’s inner value but the value of the disability community.

The other three domains are external and focused on communal aspects of disability (Putnam, 2005). The fourth domain is “common cause,” which represents the acknowledgment that disabled people share common experiences and desires for policy change. This domain has four sub-domains involving beliefs that (a) disabled people share similar experiences, (b) some experiences should be modified or changed, (c) the contributing factors to modifiable

experiences are similar, and (d) addressing their experiences as a group issue involves developing a common political agenda. The fifth domain is “policy alternatives,” which represents the acknowledgment that public policies shape opportunities to pursue the modification of the environment and the improvement of individual capacity and the belief that better policies are possible. This domain has three sub-domains involving beliefs that (a) disability is not characteristic of the individual, (b) contributors to the disability experience can be identified and addressed, and (c) opportunities to reduce or eliminate disability and to condition the disability experience are influenced by public policy. Finally, the sixth domain is “engagement in political action,” which involves three sub-domains: (a) the belief that people experiencing disability are a political constituency group, (b) disability constituency groups represent political minority groups, and (c) engagement in political action by, for, and on behalf of constituency groups can effect policy change. The final three domains highlight the importance of disabled people joining together to fight discrimination and work towards policy change.

It should be noted that this model focuses on explaining disability identity itself, rather than the process of disability identity development, making it the first of its kind. Rooted in Hahn’s (1994) minority model of disability and adopting a social model of disability perspective, this model calls attention to the social environment as being often more disabling than the individual’s impairment. Putnam’s (2005) model is also founded on the association between disability activism and disability identity. Hahn and Belt (2004) and Caldwell (2011) have gathered empirical evidence that supports the assumption that a strong disability identity is rooted in a personal commitment to social justice.

While Putnam (2005) believed that this conceptual model could guide empirical analysis of disability identity, to date, there has been no empirical research to support this model nor to test and confirm its validity. The apparent lack of empirical support and validity is its main critique. Critics of the model also argue that it is theoretically tailored to a small fraction of the disabled population who are politically active (Gagliano, 2021). This particular conceptualization of disability identity may not represent the everyday experience of many who have a disability.

3.2.2.2. Dunn and Burcaw's Narrative Accounts of Disability Identity. Dunn and Burcaw (2013) developed a theoretically-based thematic model of disability identity development. While they did not set out to introduce a new model, Dunn and Burcaw's research established a conceptual model that highlights how critical the personal meaning taken from the disability experience is to identity development. To review disability identity as a type of narrative identity, Dunn and Burcaw (2013) utilized a narrative research approach (Riessman, 2008) to carry out the qualitative exploration of six published narratives (e.g., books, articles, blogs) written about disability experiences by people with disabilities. Narrative identity is "the internalized and evolving story of the self that a person constructs to make sense and meaning out of his or her life" (McAdams, 2011, p. 99). The published narratives were examined for illustrations of themes associated with disability identity development (Dunn & Burcaw, 2013). They examined narratives through the lens provided by existing themes drawn from disability identity research (i.e., affirmation of disability, communal attachment, self-worth, pride, discrimination, and personal meaning).

Dunn and Burcaw's (2013) model illustrates six disability identity themes: (a) communal attachment, (b) affirmation of disability, (c) self-worth, (d) pride, (e) discrimination, and (f)

personal meaning. The first theme, “communal attachment,” is represented by negotiating and acknowledging both one’s disability and those of others, relationships with others with disabilities, and connections to the disability community. The second theme, “affirmation of disability,” is represented by accepting difference, rejection of pity, and having a positive view of oneself with a disability. The third theme, “self-worth,” is represented by valuing one’s strengths and capabilities as well as the opportunities that disability presents and returning to work and socializing with friends. The fourth theme, “pride,” is represented by embracing disability and the involvement in and adoption of disability culture. The fifth theme, “discrimination,” is represented by the negative experiences associated with disability, including the stigma of disability, exclusion, and bullying. The sixth theme, “personal meaning,” is represented by listening to one’s body and surroundings and acceptance of the body and the world for how it is. The themes illustrate different aspects of *being disabled* as well as factors important to the development of a positive disability identity.

Burcaw, who self-identifies as a person with a disability, like many other disability identity theorists (Forber-Pratt & Zape, 2017; Gibson, 2006; Gill, 1997), brought a first-hand experience of disablement to the development of this model. Unlike the other models discussed above, this model focuses on explaining disability identity itself rather than the process of disability identity development. This model uniquely introduces personal meaning as a theme of disability identity. Personal meaning is described as “searching for significance, engaging in sense-making, and finding benefits associated with disability” (Dunn & Burcaw, 2013, p. 150). Research by Zapata (2019) lends support to including personal meaning in the factor structure of disability identity. In the evaluation of a new personal disability identity

scale, Zapata found that their derived model of personal meaning in disability was consistent with the theme of personal meaning theorized by Dunn and Burcaw (2013). Aside from Zapata (2019), no empirical research exists to support this model in part or as a whole.

Dunn and Burcaw (2013) acknowledge that there are likely quite a few more themes that could inform our understanding of the development, benefits, and role of disability identity. They suggest an inductive narrative approach to disability narratives, as compared to the deductive approach they used, which will allow for the excerpts of disabled people's narratives to suggest additional categories and themes related to disability identity. Gagliano (2021) criticized this model for a lack of structural specificity, which makes it difficult to directly test. In addition, the model has also been criticized for its methodology, as it was developed from the analysis of existing works rather than original data collection (Forber-Pratt & Zape, 2017).

3.2.3. Synthesis of Research on Being Disabled

The models discussed above illustrate the variation in and complexity of conceptualizations of disability identity. The existing models and empirical evidence indicate that disability identity is an under-researched area with little consensus on what constitutes *being disabled*. That said, there are some commonalities across the models. First, most of the models in the disability identity literature are developed by people with disabilities (Dunn & Burcaw, 2013; Forber-Pratt & Zape, 2017; Gibson, 2006; Gill, 1997). As such, the disabled authors bring an insider's perspective to understanding disability identity development. This perspective likely offers a different point of view of what it means to *be disabled* than what a person with an outsider perspective might have (Brown, 2010; Dembo, 1964; Wright, 1960).

Those with an insider's perspective of disability have valuable knowledge that can enrich research through differing viewpoints of disablement that are filtered through personal experience and individual beliefs (Brown, 2010).

Second, across the models, disability identity is commonly conceptualized as both personal and intrinsic to the individual and as communal and shared. The majority of the models emphasize that disability identity is multi-dimensional (Gill, 1997; Putnam, 2005; Caldwell, 2011; Dunn & Burcaw, 2013; Forber-Pratt & Zape, 2017). The model components (see Table 2) illustrate both internal and external dimensions. Only Gibson's (2006) model was noted as being overly "individualistic." This commonality across the models suggests that being disabled is not only a matter of one's personal beliefs and relationship to their impairment but also about the shared experiences and cultural understandings of the disability minority group. Third, all of the models share an emphasis on the interactions that individuals have with others with disabilities and the influence these interactions have on integrating disability into the self-concept. This suggests that disability identity develops in relation to others.

Table 2

Models of Disability Identity: Components

Model	Components
Disability Identity Development Models	
Gill's (1997) Disability Identity Development Model	• Coming to feel we belong • Coming home • Coming together • Coming out
Gibson's (2006) Disability Identity Development Model	• Passive awareness • Realization • Acceptance
Caldwell's (2011) Disability Identity Thematic Model[a]	• Resistance, claiming personhood and voice • Connection with disability community • Reclaiming disability and personal transformation • Interconnection with broader disability rights movement • Bond with social justice and interdependency
Forber-Pratt and Zape's (2017) Model of Social and Psychosocial Disability Identity Development[a]	• Acceptance status • Relationship status • Adoption status • Engagement status
Disability Identity Models	
Putnam's (2005) Political Disability Identity Model	• Self-worth • Common cause • Pride • Discrimination • Policy Alternatives • Engagement in political action
Dunn and Burcaw's (2013) Narrative Accounts of Disability Identity	• Communal attachment • Affirmation of disability • Self-worth • Pride • Discrimination • Personal meaning

Note. [a] Indicates empirical study

Fourth, at least four of the models are rooted in a social model understanding of disability (Caldwell, 2011; Gibson, 2006; Gill, 1997; Putnam, 2005). Two models, in particular, are indicated to have been developed using a North American model perspective (Putnam, 2005; Gibson, 2006). Given this foundation, these models frame disabled people as a minority group with a socially mediated minority group identity. As such, these models are structured with consideration for the barriers to positive group identity.

Of the models discussed in this section, four specifically focus on disability identity development (Caldwell, 2011; Forber-Pratt & Zape, 2017; Gibson, 2006; Gill, 1997), while only two address what constitutes disability identity itself (Dunn & Burcaw, 2013; Putnam, 2005). In the literature, there has been much consideration given to the factors involved in the process of disability identity development as well as the stages, statuses, and themes that characterize this process, but less attention has been given to the elements that comprise disability identity (Forber-Pratt et al., 2017). This paucity of research on what constitutes disability identity seems to be a consequence of *disability identity* models and *disability identity development* models being largely treated synonymously. The majority of the models focus on disability identity development, suggesting that disability identity is malleable. Research supports the fact that identities are not fixed but have the capacity for movement (Schöpflin, 2001). The problem with the predominance of development models in disability identity discourse is that the focus is on development rather than the characteristics, dimensions, or factors that constitute disability identity itself. Researchers and practitioners must consider how they can be certain of the processes that lead to a coherent disability identity when there is a lack of consensus understanding of what it means to *be disabled*.

The models discussed in this section are largely theoretical in nature, with limited empirical evidence in support (Dunn & Burcaw, 2013; Gibson, 2006; Gill, 1997; Putnam, 2005). Two models (Gibson, 2006; Gill, 1997) were developed based on the authors' clinical work, and two models (Dunn & Burcaw, 2013; Putnam, 2005) were conceptualized based on prior literature. Caldwell's (2011) and Forber-Pratt and Zape's (2017) models were developed from empirical research conducted by the authors. The number of theoretical models compared to the number of models founded on the empirical study of disabled people presents questions concerning the validity and applicability of the models. Additionally, the two models that were developed through qualitative empirical study utilized low sample sizes of individuals from specific groups (i.e., disabled people who were leaders in the self-advocacy movement and college students with disabilities) that may not be representative of the general population of disabled people. Given the way the models were developed, further empirical research is warranted to better understand the posited conceptualizations of disability identity.

Of the disability identity models, only Gibson (2006) and Forber-Pratt and Zape (2017) have conducted subsequent empirical research that has tested the model in full (Gibson et al., 2018; Forber-Pratt et al., 2020). Meanwhile, limited research has found support for parts of three other models (Gill, 1997; Dunn & Burcaw, 2013; Forber-Pratt & Zape, 2017), and Putnam (2005) and Caldwell (2011) have not been empirically studied at all. This paints a troubling picture of the state of disability identity research, which has been an understudied area. Forber-Pratt and Zape (2017) reported that they conducted a PsycINFO search of peer-reviewed, scholarly articles published during 1985-2016 and found only 52 articles that contained the exact phrase: "disability identity." A systematic review of the literature on

disability identity development (Forber-Pratt et al., 2017) identified only 41 empirical articles. The lack of, or nonexistent, empirical support for many of the conceptualizations put forth in the literature makes It challenging to trust existing understandings of what it means to be disabled.

What is known from the limited theoretical and empirical evidence to date is that to *be disabled* is socially, individually, and historically constructed (Forber-Pratt et al., 2019). The various models in this section illustrate the different conceptualizations that can be created depending on the author or sources used. Disability identity shapes the way people see themselves, their bodies, how they interact with the world, and how they adapt to disability (Forber-Pratt et al., 2017). The number of different components that constitute each model demonstrates the wide spectrum of experiences that may constitute what it means to be disabled. While several models attempt to conceptualize this phenomenon, the lack of empirical research suggests further study is needed. In addition to the lack of research that explores disability identity using the models, there is limited research that examines disability identity in people with SCI (Griffin-Fillier, 2014; Hernandez, 2005; Holden, 2013; Ostrander, 2008; Yoshida, 1993). Furthermore, no research has used a disability identity model to examine *being disabled* with people with SCI, nor women athletes who have acquired a SCI for that matter. This represents a gap in the literature and a large gap in our understanding of what it means to be disabled. The key problems with present conceptualizations of *being disabled* are the obfuscation of disability identity with disability identity development and the limited to nonexistent research exploring the phenomenon, particularly as it relates to women athletes who have acquired a SCI.

3.3. Living with (Disability)

To live with means to put up with, to come to terms with (live, 2021). Individuals with SCI must come to terms with living with a serious chronic illness and the experience of acquired disability. As a consequence of this experience, individuals must personally adapt to both their diminished functional capacity and their altered relationships and interactions with the physical and social environment (Livneh & Martz, 2012). Adaptation to acquired disability is a "process of responding to the functional, psychological, and social changes that occur with the onset and experience of living with a disability, chronic illness, or associated treatments" (Bishop, 2005a, p. 6). There are many ways an individual can adapt to living with disability. Disabled people can adapt by trying to accommodate and flow with the experience of illness, or they could attempt to ignore it, minimize it, struggle against it, reconcile themselves to it, or embrace it (see Charmaz, 1991; Radley, 1991). There are numerous psychosocial factors in one's daily life that one must navigate to adapt to such an experience.

Living with disability is characterized by living in a constant state of adaptation. What this means is that a person who is living with disability has to come to terms with, or put up with, the fact that their lives are continually adapting to what is in front of them. Given this characterization of *living with disability*, there is a need to review models of adaptation to acquired disability. There is a wide spectrum of views on adaptation to acquired disability. In the sections that follow, several of the most prominent models that aim to explain what it means to live with acquired disability through the process of adaptation to disability will be introduced: (a) Livneh's unified stage model of adjustment to disability (Livneh, 1986), (b) the integrated model of psychosocial adjustment following acquired disability (Kendall & Buys,

1998), (c) the psychosocial adaptation to chronic illness and disability model (Livneh, 2001, 2021), (d) Devins' illness intrusiveness model (Devins et al., 1983; Devins, 1994), and (e) Bishop's disability centrality model (Bishop, 2005a, b; Bishop et al., 2007; Bishop et al., 2009).

3.3.1. Livneh's Unified Stage Model of Adjustment to Disability

Historically, the dominant way of understanding what it means to *live with disability* has been through the lens of linear, stage-like models of psychosocial adaptation to acquired disability (Livneh, 1986). Livneh (1986) developed the unified stage model of adjustment to disability (hereafter referred to as the unified model) to unify and incorporate elements of over 40 existing stage models of adjustment to acquired physical disability. According to Livneh (1986), a basic assumption of stage models is that adaptation is a dynamic and ongoing process in which adjustment is considered the final positive outcome. The unified model argues that the process of change associated with acquired disability is defined by a stable sequence of stages. Livneh (1986) postulated five stages of adjustment to an acquired physical disability: (a) initial impact, (b) defense mobilization, (c) initial realization, (d) retaliation, and (e) final adjustment or re-integration.

The first stage is "initial impact," which involves the first reactions of the individual and family to the sudden onset of physical disability. This stage has two sub-stages: (a) shock and (b) anxiety. Individuals living with disability at this stage may experience shock, which is described as numbness, detachment, and emptiness; thoughts become disorganized, disoriented, and confused; and many people find it difficult to concentrate and make simple decisions (Gunther, 1971; Livneh & Antonak, 1997). They may also experience anxiety, which is described as an

overwhelming feeling that, in extreme cases, can trigger a panic attack. The individual may be panic-stricken, and their normal thinking may be disrupted.

The second stage is "defense mobilization," which involves the individual regrouping their defenses to address the initial impact. This stage has two sub-stages: (a) bargaining and (b) denial. Living with disability, at this stage of adaptation, means that the individual may resort to bargaining, which is a short-term attempt to negotiate with a higher power for a full recovery by promising to pay penance for past wrongdoing, donate to charitable causes, or do other benevolent actions (Livneh, 1991). They may also attempt to defend themselves through the use of denial, which can be a more long-lasting defense mechanism in which the individual denies or negates the disability and its ramifications to protect themself from fear of the unknown and immense emotional sadness.

The third stage is "initial realization," which indicates that living with disability involves the initial or partial recognition of the disability and its impact on the individual's life. This stage has two substages: (a) mourning and/or depression and (b) internalized anger. Whereas depression is generally experienced for a longer duration, mourning is typically experienced for a shorter duration as the individual grieves the specific loss of bodily function and their previous way of life. Depression involves more general cognitions and emotions, such as fear of an uncertain future (Livneh, 1986). At this stage, individuals living with disability may also experience internalized anger, which involves self-blame, guilt, and shame. The individual may blame themself and view disability as punishment from a higher power for some perceived wrongdoing (Marini & Glover-Graf, 2011), which may lead to self-abuse or self-injurious

behavior. Self-blame may be amplified and make adaptation even more difficult if the individual was the cause of their injury or illness (Livneh & Antonak, 1997).

The fourth stage is “retaliation,” which Livneh and Antonak (1997) refer to as externalized hostility, a rebellion against a fate of perceived dependency. During this stage, living with disability may mean that the disabled person directs anger at the external world (e.g., people, objects, or environmental conditions; Livneh, 1991). They may blame or lash out at others for no apparent reason due to frustration and anger, or they may choose more passive-aggressive behavior such as uncooperativeness, manipulativeness, or being provocative. The fifth and final stage is “final adjustment or reintegration,” which portrays cognitive, affective, and behavioral substages. At this stage, living with disability means that people are cognitively able to acknowledge or accept their disability and its permanency, integrate disability into their self-concept, reappraise the life domains they value most, and seek meaning in new pursuits (Livneh & Antonak, 1997). Emotionally, individuals feel positive, content, and confident in themselves, and they can discuss their disability without becoming upset. Behaviorally, people begin to actively pursue social, academic, and/or vocational goals and learn how to successfully navigate physical and social environmental barriers.

Figure 5

The Unified Stage Model of Adjustment to Disability

Unified Stage Model of Adjustment to Disability (Livneh, 1986)

The stages included in the unified model were found in most of the stage models that Livneh (1986) reviewed. The ordering of the stages was also reflective of the consensus among reviewed models. The unified model recognizes that *living with disability* is a dynamic process

of adaptation that includes cognitive, affective, and behavioral components. It posits that the onset of disability disrupts an individual's psychological equilibrium, and, as such, the psyche must be adjusted for successful adaptation (Livneh, 1986). Employing an individual psychological approach, the model suggests the individual works through a series of stages by changing their emotional and cognitive state. Based on Livneh's (1986) explanation of the unified model, the role of adaptation in living with disability is to achieve a benchmark of acceptance of and comfort with disability, as well as reintegration into society. As such, the unified model presumes that life with disability ends, or stabilizes, at adaptation. Livneh (1991) provides the caveat that people may regress to earlier stages, skip stages, or overlap stages, which acknowledges that, when living with disability, periodic setbacks may occur, and there are individual differences in how people respond to disability.

While some researchers argue that there is little empirical support for the stage model of adjustment (Chan et al., 2009; Olkin, 1999), others have found support for elements of the unified model. In a sample of (n = 214) rehabilitation facility participants with acquired physical disabilities, Livneh and Antonak (1991) investigated eight psychosocial reactions to disability hypothesized to occur in a temporal order. They found limited support for the temporal structure of reactions to disability. Five reactions (shock, anxiety, internalized anger, hostility, and depression) were reported much more frequently in the past, closer in time to the disabling accident, than in the present. These reactions were distinguished from two reactions (acknowledgment, adjustment) that had correlational support during the later phase of disability, further from the initial injury. They also found disabled people may indeed skip a particular reaction, as well as regress to earlier reactions.

In a brief report on the coping responses of (n = 24) patients with SCI, Belciug (2001) found evidence to support the initial realization and retaliation stages of the unified model. They found that the participant responses were similar to the description of individuals' reactions at these stages – socially withdrawn, dependent, bitter, and resentful. Lequerica and colleagues (2010), in a study of stress appraisal in women with SCI (n = 50), found support for the initial impact stage of adjustment. They found a qualitative difference between the early temporal phase of recovery and the women's experiences temporally further from injury onset. In a study of adaptation and coping in patients living with end-stage renal disease on hemodialysis, Santiago (2010) found evidence to support the temporal nature of the adaptation process toward advanced stages of psychosocial adaptation. They also found evidence that stages are transitional in nature, although some individuals may never reach the final stage in the process. The empirical evidence established from the studies above indicates support for the existence and temporality of several elements of the model, which suggests that individuals living with disability may experience many of the reactions in an anticipated order.

Other researchers have found conflicting evidence. Regarding the initial realization substage of depression, researchers have found evidence that not all individuals report experiencing depression following a physical disability (Wortman & Silver, 1989). This means that some individuals may not experience this substage when living with disability. Wortman and Silver (1989) also showed that while many people have been found to progress from initially higher levels of distress to lower levels over time, others show no signs of intense distress, and some experience heightened distress for longer periods of time.

There are several criticisms of the unified model. Researchers argue that while stage models may adequately represent the general progression toward adjustment that individuals experience over time (Davis, 1987), they do not sufficiently address the complexity or recurrent nature of the psychosocial adjustment process (Kendall & Buys, 1998; Yoshida, 1993). Yoshida (1993) argues that stage models do not adequately match the subjective experience of people with acquired disabilities. This makes it difficult to understand what it means to an individual to live with disability. Kendall and Buys (1998) argue that expecting and anticipating people with acquired physical disabilities to go through specific stages is ill-advised. They claim that stage models normalize responses to disability, such as denial and depression, which may lead to passivity on the part of the practitioner as they expect certain responses from individuals and encourage fewer alternatives. Individuals who do not experience these reactions may be viewed as abnormal (Wortman & Silver, 1989). As such, implementing a stage model in practice could lead to social oppression (Kendall & Buys, 1998). There are other apparent flaws in this model. The individual psychological approach of the model ignores and minimizes the social aspects of adaptation. This means that many social, environmental, and cultural factors involved in living with disability are left unexplored. Additionally, framing the final stage of adaptation as adjustment, as done in this model, limits the possibilities for future life with disability. Livneh (1991) may have provided the caveat for a return to previous stages and reactions, but this still limits the possible reactions and experiences of life with disability.

3.3.2. Integrated Model of Psychosocial Adjustment Following Acquired Disability

To address the perceived shortcomings of the stage or linear models of adjustment, Kendall and Buys (1998) proposed the integrated model of psychosocial adjustment following

acquired disability (hereafter referred to as the integrated model). The integrated model was developed by incorporating existing knowledge about psychosocial adjustment to chronic illness and disability (e.g., Charmaz, 1995; Yoshida, 1993). The integrated model is considered a pendular model, one that posits *living with disability* involves an ongoing process of adaptation that oscillates between past perceptions of health and normalcy and a realization of the present disability (Livneh & Martz, 2012). This model postulates that adaptation to acquired disability is a recurrent process where no outcome exists. This means that there is no point at which the disability no longer affects the individual living with disability (Kendall & Buys, 1998). People with acquired disabilities will continue to live their lives with disability. Although the emotional disruption that they experience typically subsides over time, they will continue to experience periods of chronic sorrow throughout their lives.

Characterized by chronic sorrow and a pattern of despair and acceptance, the integrated model (see Figure 6) details a process in which individuals with acquired disability reconstruct the cognitive schema by which they view themselves and their experiences with disability. Cognitive schema are a person's ingrained beliefs and assumptions about themselves, others, and the environment (Beck & Weishaar, 1989) that influence their interpretation of experiences (Stewart, 1996). An individual's cognitive schema act as a prism through which their shift in life circumstances as a result of disability can be interpreted and guide their thoughts, feelings, and behaviors. Schema development and modification fluctuate through a pendulum motion as each new experience is confronted. Some try to cling to old schema due to the anxiety and uncertainty brought on by disability (Wright, 1983). Since old schema are no longer sufficient, individuals may be overwhelmed by their inability to interpret new

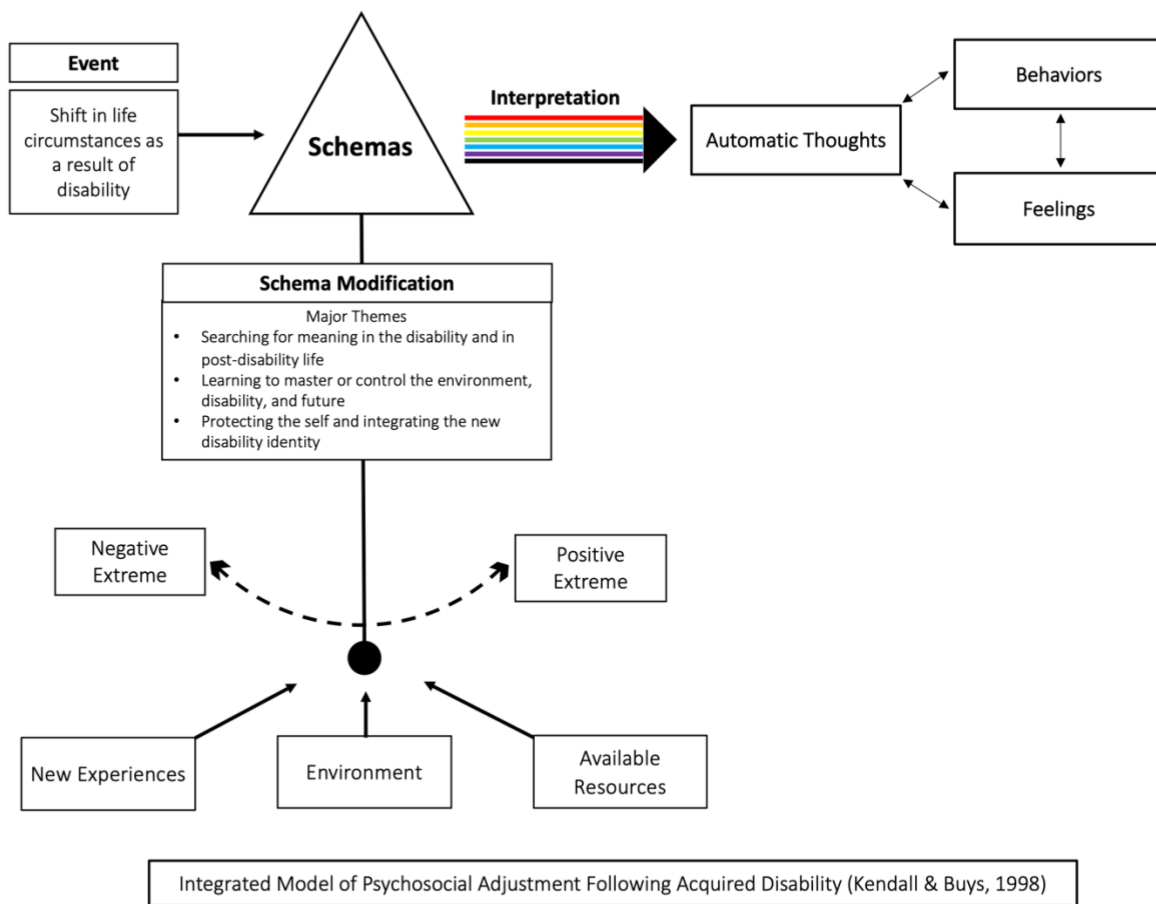
experiences, which may lead to depression as individuals realize the implications of disability (Kendall & Buys, 1998). To adapt to an acquired disability, individuals must form new positive schema of life with a disability. Along the way, they must confront environmental influences that may foster periods of sorrow, such as relationship rejection, job denial, or discrimination perceived to be because of one's disability (Graf et al., 2009; Marini et al., 2009). Information from the environment is gathered and integrated during the schema modification process to develop new schemas incrementally as new elements (e.g., experiences and resources) are encountered (Charmaz, 1995).

The initial injury phase, which is characterized by emotional responses such as anxiety, fear, and grief, is described by Yoshida (1993) as a wildly swinging pendulum. After an indeterminate amount of time, this pendulum gradually slows down until it comes to rest at a middle setpoint where the individual either develops new positive or negative schema of life with a disability (Yoshida, 1993). There are three major themes of the schema modification process: (a) searching for meaning in the disability and post-disability life; (b) learning to master or control their environment, their disability, and their future; and (c) protecting the self and integrating the new disability identity (Barnard, 1990; Kendall & Buys, 1998). Individuals with acquired disabilities form positive new schema when they can find meaning in their disability and post-disability life; master their environment, their disability, and their future; and protect their self and integrate their new disability identity (Kendall & Buys, 1998). Individuals form negative schema about life with a disability when they allow stereotypical societal expectations about disability to influence their self-worth (Charmaz, 1983). Those who develop negative schema post-injury are likely to be more susceptible to self-pity, low self-esteem, and more

frequent episodes of chronic sorrow (Marini, 2011b). Regardless, even those who develop new positive schema of life with a disability will still periodically experience times of sorrow (Kendall & Buys, 1998). The integrated model is illustrated in Figure 6, which was adapted from the writing of Kendall and Buys (1998), Beck (1991), and Yoshida (1993).

Figure 6

The Integrated Model of Psychosocial Adjustment Following Acquired Disability



Kendall and Buys (1998) identify multiple implications of the integrated model. First, living with disability may require long-term follow-up rehabilitation and community-based services as well as access to natural supports so that individuals can make use of a network of

support when recurrent adaptation problems inevitably occur. Second, living with disability is a unique experience for each individual, which means that a humanistic and phenomenological approach must be used to understand their behavior. Finally, to encourage the development of positive schema of life with disability, the model advocates for a focus on developing resources, maintaining strengths, and expanding opportunities.

While there is limited empirical support for the integrated model, researchers have suggested the process of adaptation to acquired disability can be described as recurrent (Davis, 1987). Yoshida (1993), in a study of the identity reconstruction process of (n = 35) adults with SCI, found no limit to the number of times the pendulum process could occur or the duration of the process. Charmaz (1995) also lends support to the integrated model as her results, from a study of how the body, identity, and the self intersect for (n = 55) adults with serious chronic illness, indicate that the reconstruction of self-schemas during the adaptation process happens iteratively as the individual encounters the environment. She also found that negative self-schema can lead to depression and diminished self-worth, while positive self-schema can foster a robust identity. Graf and colleagues (2009), in a study of the experience of living with disability (n = 78) by people with SCI, found support for the cognitive schema element of the model. Specifically, they indicated that individuals may cling to pre-disability schema and, as a result, find it difficult to look forward to adaptation. The empirical evidence identified above indicates support for the role of adaptation in living with disability as a recurrent, iterative process influenced by the environment as well as the cognitive schema that filters an individual's experiences of disability.

There are identifiable issues with the integrated model. Kendall and Buys (1998) describe individuals with a disability as adapting to “a nearly intolerable set of circumstances” (p. 17). This description of disability reinforces a medical model perspective of disability as a tragedy. The model lacks structural specificity. There are no easily identifiable components of the model, which may make this a difficult model to apply in practice or evaluate through empirical study. Given that this model was developed from prior literature and there is nearly non-existent research to test the model, further empirical study must be carried out to test the validity and applicability of the model.

3.3.3. Livneh’s Psychosocial Adaptation to Chronic Illness and Disability Model

Livneh (2001, 2021) also created the psychosocial adaptation to chronic illness and disability model (hereafter referred to as Livneh’s model). Livneh developed this model through a loosely structured synopsis of extant perspectives on the process of psychosocial adaptation to chronic illness and acquired disability. This is an ecological model (Livneh & Martz, 2012). It conceptualizes adaptation to acquired disability as a dynamic, complex process that involves numerous interacting factors (personal, acquired disability-related, external contextual) that lead to a multidimensional outcome (Livneh, 2001). In Livneh’s model, it is understood that *living with disability* is influenced by a series of physical, psychological, social, and environmental processes that determine the trajectory of any experience that an individual may encounter. The model includes three components: (a) antecedent events and characteristics, (b) contextual and psychosocial processes, and (c) outcomes.

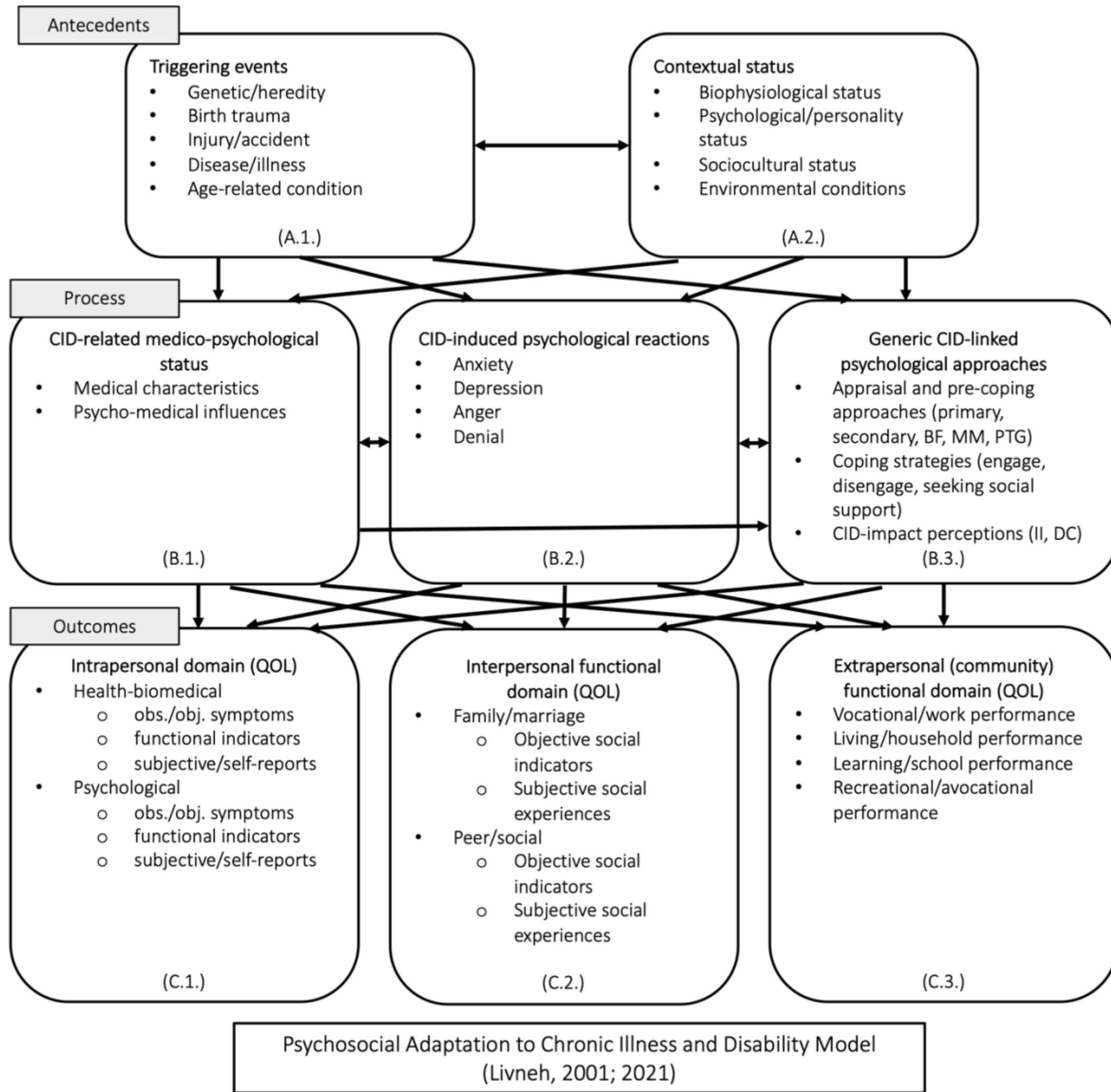
The first component is “antecedent events and characteristics,” which represents pre-acquired disability features that may have explicitly or implicitly caused the disabling condition

as well as the context in which it occurred. This component includes two interacting sets of variables: (a) acquired disability-triggering events (e.g., injury, chronic illness, maturity, genetics) and (b) contextual variables (i.e., past physical, socioeconomic, attitudinal, personality, and environmental conditions). The sets of variables included in the first component exert influence upon the sets of variables included in the second component – the process of adaptation. The second component is "process," which represents the presently influencing psychosocial processes and life contexts. The interacting variables give form to what it means to live with disability. The first set of variables included in the second component Is acquired disability-related medico-psychological status, which represents the state-like influence of medically determinable characteristics (e.g., functional restrictions, presence of pain) and psycho-medical influences (e.g., perceived uncertainty, uncontrollability, perceived stigma). The second set of variables are specific acquired disability-induced psychological reactions that serve as filtering mechanisms. These psychosocial reactions that people may report experiencing following the onset of acquired disability include anxiety, depression, anger, and denial. The third set of variables are generic acquired disability-linked psychological approaches including strategies and processes that come into focus following the onset of acquired disability. The constructs believed to fit under this umbrella of variables include appraisal and related pre-coping approaches; coping strategies; and perceptions of acquired disability impact on, intrusion into, and interference with daily life. The interacting variable sets of the second component (with the added influence of the antecedent variable sets) determine, to a large extent, the outcome of a person's psychosocial adaptation to acquired disability.

The third component is “outcomes,” which involves a set of anticipated outcomes that are indicators of quality of life across three broad life domains: (a) intrapersonal (e.g., subjective well-being, life satisfaction, perceived health), interpersonal (e.g., satisfaction with family life, peer relations, and social activities), and extrapersonal (e.g., the performance of work activities and/or recreational pursuits, living arrangements, financial status) life domains. While this component is viewed as the end product of the adaptation process, this model adopts a continuous approach to outcome conceptualization. This means that there exists a continuum of outcomes that range from nonadaptive to adaptive (Livneh, 2021). Quality of life, in this component, takes on dynamic meaning as it refers to efforts to achieve psychosocial homeostasis that has been disrupted as a result of the impact of disability as well as the attainment of person-environment congruence (Livneh, 2001). Additionally, according to this model, successful adaptation to acquired disability can be considered both the process leading to as well as a marker of quality of life across life domains. There are several interacting components featured in the model. The middle component, contextual and psychosocial processes, may be described as a moderator between the previous immutable life influences and acquired disability onset–related elements of the first component, and the person’s current quality of life in the third component.

Figure 7

The Psychosocial Adaptation to Chronic Illness and Disability Model



Livneh's (2001) model emphasizes the interaction between the individual with a disability and their environment in the first and third components. This encourages an understanding of *living with disability* that accounts for both individual and environmental influences. The model assumes that a successful adaptation outcome reflects the ability of the

individual to effectively manage both their internal and external experience as well as an improved quality of life. Despite the consideration of antecedent life context and inter- and extrapersonal outcome domains, this model takes a largely individual psychological approach to the adaptation process. While the antecedent variables are assumed to have a role in the adaptation process, they are still framed as antecedent factors rather than present and changing circumstances. As an adaptation outcome, quality of life represents an individual's efforts to reestablish psychosocial homeostasis and attain congruency between person and environment (Livneh, 2001). The outcome domains indicate that *living with disability* involves multiple dimensions.

There is limited empirical research on Livneh's model. Pedras and colleagues (2018) utilized this model to study the psychosocial adjustment of (n = 86) individuals with lower limb amputations. They found support for several elements of the model (i.e., contextual status, acquired disability-induced psychological reactions). They also found support for the negative association between traumatic stress symptoms and adjustment, as well as the mediating role of perceived social support between traumatic stress symptoms and adjustment. Martz and colleagues (2005) used structural equation modeling to test Livneh's model in a study of people with SCI that investigated the relationships between disability severity, negative affectivity, and psychosocial adaptation outcomes. They found that the hypothesized model had a moderately good fit for the data. Bhattarai (2021) conducted a study of the contextual influences and psychosocial reactions that contribute to quality of life adaptation outcomes among (n = 231) people with SCI using this model. A path analysis of the observed variables (i.e., pain, functional limitation, self-efficacy, mindfulness, and social support) and their relationship to quality of life

and acceptance revealed that the model fits the data. While they found pain and functional limitation failed to significantly predict quality of life, self-efficacy, mindfulness, and social support did significantly predict higher quality of life. Additionally, they found that only functional limitation and mindfulness contributed to the acceptance of disability. The empirical evidence discussed above shows support for many of the model's elements. This indicates that to understand what it means to live with disability, one must consider an individual's subjective evaluation of life domains and the impact of disability-related factors, psychological reactions, and socio-environmental life contexts.

Livneh's model is complex, and it relies on a large number of interacting components, which makes it difficult to validate through traditional procedures (Livneh & Martz, 2012). As such, it may require investigation through the segmented study of various components and their proposed interactions. The lack of consideration given to presently existing social, environmental, and cultural factors in the adaptation process demonstrates that the understanding of *living with disability* obtained from this model does not adequately address the psychosocial nature of life with disability. Further research should address this gap in understanding.

3.3.4. Devins' Illness Intrusiveness Model

Devins' and colleagues (Devins, 1989; Devins, 1994; Devins et al., 1983; Devins et al., 1990; Devins, Edworthy, Seland, et al., 1993; Devins, Seland, et al., 1993; Devins & Shnek, 2000) created the illness intrusiveness model from empirical research in the area of end-stage renal disease (Devins et al., 1983, Devins et al., 1990) and multiple sclerosis (Devins, Seland, et al., 1993). It proposes that the impact of acquired disability on the individual compromises their

psychological well-being, or quality of life, by temporarily or permanently reducing the positively reinforcing outcomes of participation in meaningful and valued activities as well as reducing feelings of real or perceived control to regain positive outcomes or avoid negative ones. As such, this model understands that *living with disability* involves navigating the intrusiveness of disability on an individual's lifestyle and their ability to manage their changing life circumstances. Although there have been different iterations of the illness intrusiveness model over the past 40 years, it can best be understood as including the following components: (a) disease factors, (b) treatment factors, (c) illness intrusiveness, (e) personal control, and (f) psychosocial (or subjective) well-being (Devins, Edworthy, Seland, et al., 1993; Devins, Seland, et al., 1993).

The first component of the illness intrusiveness model is "disease factors," which focuses on changes, triggered by disability, to the person's physical body, otherwise considered internally-induced stressors. This component includes factors such as the severity of symptoms, pain, fatigue, and functional limitations. The second component is "treatment factors," which focuses on externally-derived influences. This component includes such factors as the nature of therapy, treatment environment, the time required for treatment, and side effects. The first two components include factors that may influence the intrusiveness of acquired disability. The third component is "illness intrusiveness," which represents acquired disability-triggered disruptions to participation in meaningful lifestyles, activities, and pursuits that stem from the aggregated contributions of internally-induced stressors and externally-derived influences (Devins, 1989; Devins, Edworthy, Seland., 1993; Devins, Seland, et al., 1993). This component is viewed as a set of events that people frequently experience when living with disability.

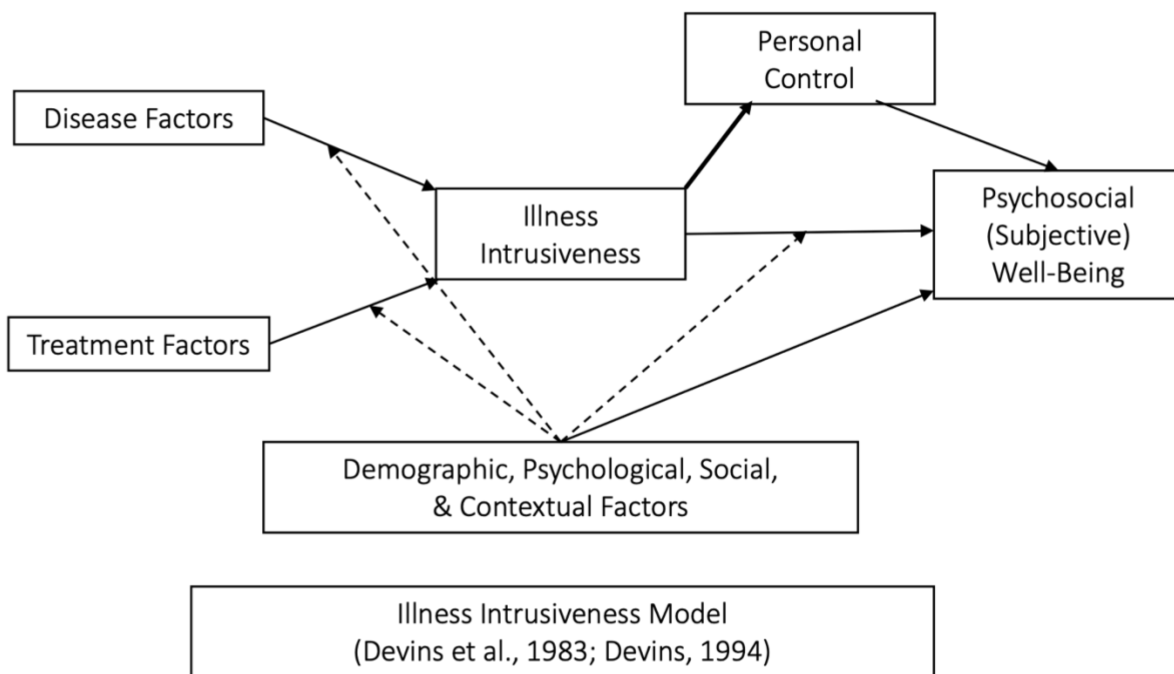
Fundamentally, illness intrusiveness acts as the moderator between internal and external influences and adaptation outcomes. The fourth component is “personal control,” which represents the direct and indirect influence of illness intrusiveness on an individual’s perceptions of their capability to influence or control positive life outcomes. The degree to which an individual perceives they are capable of controlling life outcomes directly influences their psychosocial well-being. According to the illness intrusiveness model, illness intrusiveness and personal control are the main mechanisms through which acquired disability-triggered lifestyle disruptions can have a harmful impact on the individual. They do so by operating to reduce the availability and accessibility of positive experiences that stem from personally valued activities and interests and/or minimize the individual’s ability to exert personal control over valued life interests and experiences. The final component of the model is “psychosocial well-being,” which is an outcome indicator of the impact of illness intrusiveness and diminished perceptions of personal control on psychosocial adaptation to acquired disability. In the illness intrusiveness model, psychosocial adaptation is indicated by measures of psychosocial well-being, which is viewed as a dimensional construct that ranges from emotional distress to emotional well-being (Devins et al., 1983; Devins, Edworthy, Seland, et al., 1993, Devins, Seland, et al., 1993). The components are said to follow a quasilinear progression toward the described outcome variables (Livneh et al., 2014).

A later iteration of the illness intrusiveness model (Devins & Shnek, 2000) has recognized the direct and moderating influence of several factors: (a) demographic (e.g., age, socioeconomic status), (b) psychological (e.g., self-concept, life stage), (c) social (e.g., stigma, culture), and (d) contextual (e.g., environmental stressors and facilitators). These factors are

regarded in the revised model as forces that could potentially interact with ’ach of the model's existing components. This means that the model recognizes the role of adaptation in living with disability involves the individual navigating psychological, social, and environmental factors and their influence on disability-triggered disruptions to their life. Furthermore, the final component of psychosocial well-being is portrayed as a facet of an overall quality of life outcome component.

Figure 8

The Illness Intrusiveness Model



Devins’ model takes a narrower view of adaptation to acquired disability (Livneh et al., 2014). When compared to other models, the illness intrusiveness model incorporates a smaller number of overall variables while focusing particularly on one important moderating variable (i.e., illness intrusiveness). According to the illness intrusiveness model, illness intrusiveness

links the antecedent components with the outcome component of quality of life. This understanding of adaptation to acquired disability indicates that illness intrusiveness is the single most influential variable on an individual's experience of living with disability.

The illness intrusiveness model has been met with much empirical support. It has been consistently validated with various groups of people with acquired disabilities (Livneh & Martz, 2012). In a study to determine the direct and indirect effects of impairment on illness intrusiveness in (n = 189) people with multiple sclerosis, Bouchard and colleagues (2017) conducted a path analysis that revealed a model consistent with the illness intrusiveness model, which predicts illness intrusiveness can be explained by disease and treatment factors. In a study of the determinants of illness intrusiveness and psychosocial well-being in (n = 94) people with multiple sclerosis, Devins, Seland, et al. (1993) found support for the illness intrusiveness model. They found both illness intrusiveness and personal control to be significantly associated with psychosocial well-being; increased psychosocial well-being was associated with both increased personal control and decreased illness intrusiveness. They also found support for the assertion that illness intrusiveness impacts psychosocial well-being, in part, by decreasing personal control. Additionally, their results indicated that disease factors (i.e., burden of illness, functional deficits, physical disabilities, and fatigue) were significant determinants of the perception of illness intrusiveness in multiple sclerosis. Finally, their finding that increased illness intrusiveness was associated with the occurrence of stressful life events suggests that the psychosocial impact of chronic and life-threatening illnesses must be considered within the broader life context of affected individuals. Altaras and colleagues (2022) examined the direct and indirect effects of disability, depression, and anxiety on perceived

illness intrusiveness in (n = 72) people with multiple sclerosis. They found higher disability to be associated with illness intrusiveness, while depression and anxiety served as significant mediators of the relationship between disability and illness intrusiveness.

Several studies involving end-stage renal disease patients have established that greater perceived illness-related disruption of lifestyle and social activities (illness intrusiveness) is predictive of poorer emotional well-being (Devins et al., 1983; Devins et al., 1990; Devins et al., 1997). Devins and colleagues (1990) found that perceived illness intrusiveness correlated significantly with disease and treatment factors, as well as fatigue and difficulties in daily activities. Devins and colleagues (1997) examined the moderating effects of self-concept on the psychosocial impact of illness intrusiveness in (n = 101) end-stage renal disease patients. They found illness intrusiveness and emotional distress to be significantly and positively correlated in patients who perceived themselves as similar to the chronic kidney patient stereotype. As for those who saw themselves as dissimilar to the stereotypical chronic kidney patient, increasing illness intrusiveness was unrelated to distress. In a study of illness intrusiveness as an underlying determinant of the psychosocial impact of chronic illness on people with multiple sclerosis (n = 94) and end-stage renal disease (n = 101), Devins, Edworthy, Paul, et al. (1993) found that illness intrusiveness was significantly correlated with depressive symptoms in both groups. The empirical evidence across illness groups identified above indicates support for much of the illness intrusiveness model elements, including the key mechanisms influencing psychosocial well-being. The study results illustrate the role of adaptation in living with disability as putting up with meaningful lifestyle disruptions and coming to terms with one’s control over their changing life circumstances as a result of disruptions.

Altaras and colleagues (2022) argue that while illness intrusiveness has been widely studied across chronic illnesses, the majority of studies have focused on the unified construct, failing to examine the individual components of the construct. Livneh and Martz (2012) suggest that the illness intrusiveness model pays minimal attention to the role of other coping modalities in psychosocial adaptation. With such a focus on disruption to meaningful lifestyles, activities, and pursuits, the illness intrusiveness model pays overwhelming attention to the negative aspects of living with disability. There is no evidence of consideration for positive aspects of adaptation or living with disability.

3.3.5. Bishop's Disability Centrality Model

Bishop (2005a, 2005b; Bishop et al., 2007; Bishop et al., 2009) proposed the disability centrality model, an ecological model of psychosocial adaptation to disability. The disability centrality model was developed by drawing on elements of the illness intrusiveness model (Devins, 1994; Devins et al., 1983), Livneh's (2001) psychosocial adaptation to chronic illness and disability model, and Wright's (1960, 1983) value change theory of adjustment. According to Bishop (2005a), adaptation to disability "is defined as the individual's personal and highly individual response to disability- or illness-related disruptions across a wide range of life domains. The disruptions may be experienced in interpersonal relationships, in interaction with the physical environment, and as changes in psychological or emotional health and function" (p. 7). The process of adaptation is described as both multidimensional and subjective (Bishop, 2005a). In the disability centrality model, *living with disability* is understood to be a continuous, dynamic state of adapting to disrupted valued life domains. The disability centrality model has

four broadly defined components: (a) Devins' concept of illness intrusiveness, (b) disability centrality, (b) value change and adaptation, and (c) overall quality of life.

The first component of the disability centrality model is the underlying elements of the illness intrusiveness model, which includes the concept of illness intrusiveness, viewed as a prime moderator of the impact of factors related to acquired disability on quality of life domains. As suggested by Devins (1994), after acquiring a disability, an individual may experience changes (often reductions) in quality of life that act to (a) diminish satisfaction with centrally important life domains (i.e., domain satisfaction), (b) decrease perceived control over valued life outcomes (i.e., domain control), and/or (c) increase the frequency and magnitude of negative emotions experienced. The psychosocial mechanisms of domain satisfaction and domain control originated with Devins and colleagues (1983). These two concepts link the impact of acquired disability to quality of life. Domain satisfaction refers to the level of satisfaction an individual receives from valued life domains. Domain control refers to an individual's ability to control changing life conditions (e.g., social, vocational, environmental) and obtain positively valued life outcomes or avoid negative ones. The second component is the psychosocial concept of "disability centrality," which contains an assessment of the degree to which valued life domains (domain satisfaction) are disrupted by acquired disability, and an assessment of the importance of valued life domains to the disabled individual in terms of the impact on overall quality of life. This concept of disability centrality reflects the homeostatic, dynamic interaction between domain importance and domain satisfaction. It also reflects the relative significance individuals assign to various quality of life domains. Individuals living with

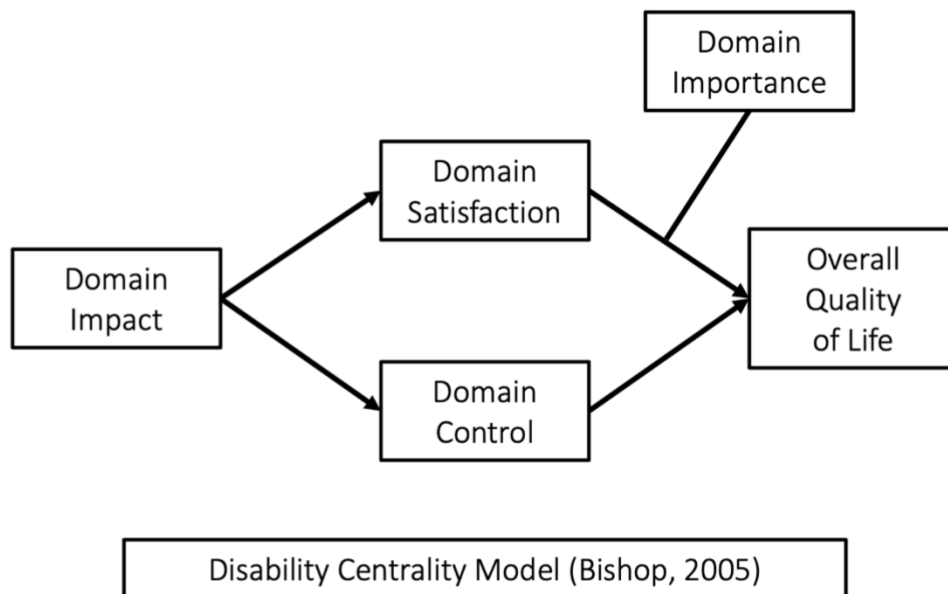
disability must come to terms with the loss of valued life domains as a result of acquired disability.

The third component is “value change and adaptation,” which represents an individual’s response to changes (often a reduction) in overall quality of life. The model explains that disabled individuals seek to maintain and maximize an internally set overall quality of life by minimizing gaps between present and desired quality of life. Bishop (2005b) argues that, in response to reductions in quality of life brought on by acquired disability, people make adaptive changes to their external conditions or through a process of value change. Similar to Wright’s (1960, 1983) theory of adjustment, this process of value change involves compensating for the loss of central or important life domains that the individual can no longer engage in due to disability by developing new valued interests in life domains that fit their capabilities. There are three possible outcomes for individuals following the reduction of perceived quality of life brought on by acquired disability. They may attempt to close the gap between present and desired quality of life by shifting the importance they place on certain central domains to peripheral domains less affected by disability, employing strategies to increase perceived control over their health and environment to reduce the impact on perceived domains of importance, or, alternatively, do nothing to improve control or change the importance assigned to life domains and allow the diminished quality of life to continue (Bishop, 2005a). The fourth component is the multidimensional, summative construct of “overall quality of life,” which is viewed as the overarching outcome criterion of adaptation to acquired disability. Bishop argues that the impact of an acquired disability can be assessed by a subjective quality of life measure. Overall quality of life is an individual’s perceived satisfaction with various life domains (e.g.,

physical, psychological, social, familial, financial, spiritual) that may be disproportionally influenced by individual differences in the life domains perceived to be most important. As such, Bishop understands quality of life as an individual's subjective overall perception of psychosocial adaptation to life with a disability. This also means that quality of life may reflect a global assessment of *living with disability*.

Figure 9

The Disability Centrality Model



The disability centrality model assumes that disability centrality and multidimensional quality of life exist in a continuous, dynamic, interactive loop, which suggests quality of life perceptions, domain importance, and domain satisfaction change over time (Livneh et al., 2014). The model has a more fully developed conceptualization of quality of life than the illness intrusiveness model (Livneh & Martz, 2012). It can link the illness intrusiveness model to a broader understanding of the concept of quality of life and its multidimensional structure.

Incorporating the theoretical framework and the supportive findings generated by the illness intrusiveness model, the disability centrality model also draws on the strengths of Wright's (1983) value change theory. The shift in importance and prioritizing of quality of life domains posited by Bishop is reminiscent of Wright's views on the significance of value changes following the onset of acquired disability, such as subordinating physique and enlarging the scope of values.

As one of the newest models of psychosocial adaptation to acquired disability, there has been less time to accumulate empirical evidence in support of the disability centrality model. That said, there is support for the concepts of domain centrality and domain control (Bishop, 2005b; Bishop et al., 2009). In a study of (*n* = 72) college students with disabilities, Bishop (2005b) found quality of life and psychosocial adaptation to acquired disability to be positively correlated. There was also a correlation found between satisfaction and perceived control in relation to the impact of acquired disability and quality of life. Bishop and colleagues (2007) evaluated the disability centrality model with a sample of (*n* = 98) adults with multiple sclerosis. They determined that their results supported a number of the model elements and relationships. Their evidence supported the mediating role of perceived domain control and satisfaction in the relationship between the perceived impact of disability and quality of life. They also found evidence to support the mediating role of domain importance in the relationship between domain satisfaction and quality of life. Additionally, their results indicated that overall quality of life represents an appropriate summative measure of psychosocial adaptation. Grist (2010) found evidence to support Bishop's model in a study of (*n* = 160)

community-dwelling older adults with physical disabilities. They found that adaptation to disability was positively related to quality of life among older adults with physical disabilities.

Mackenzie and colleagues (2015) assessed the applicability of the model with (*n* = 125) people with traumatic brain injury living in the community. They found that domain satisfaction and domain control mediated the effect of traumatic brain injury on quality of life. They also found that domain importance moderated the effect of domain satisfaction on quality of life. Their findings indicated that the disability centrality model is appropriate for use in predicting quality of life and psychosocial adaptation in people with traumatic brain injury. The empirical evidence gathered from the studies discussed above demonstrates strong support for the relationships between the elements of the disability centrality model. This evidence also indicates that understandings of *living with disability* should incorporate the elements of the disability centrality model discussed here.

There is some critique of the disability centrality model. Bishop (2005b) concedes that there is no universal agreement on what should be included in quality of life domains. Without a consensus on the life domains to be assessed when evaluating adaptation to acquired disability, it is difficult to determine which domains should be considered to understand *living with disability*. Grist (2010) argued that the model does not consider the possible influence of age of disability onset on the relationship between quality of life and adaptation to disability. As valued life domains may be dramatically different depending on the age of disability onset, it may be important to further explore the influence of such a factor. Additionally, this model focuses on much fewer factors than its predecessors, which means there is a lack of

consideration for many psychological, social, and environmental factors included in other models.

3.3.6. Synthesis of Research on Living with Disability

The models discussed above illustrate various prominent conceptualizations of psychosocial adaptation to acquired disability as well as variations in understanding of what constitutes *living with disability*. Despite how different the models are, commonalities do exist. To echo a slogan of the disability rights movement, "nothing about us, without us" (Franits, 2005). In simple terms, this means no course or principle of action concerning people with disabilities should be decided or adopted without the input or participation of disabled people. Of note, each of the models in this section on living with disability were developed by nondisabled people. As a consequence, the literature lacks an insider's perspective, one that may provide a different view than that of an outsider, and valuable knowledge filtered through personal experience that could enrich research (Brown, 2010). Without the voice of disabled people, research about the acquired disability experience risks searching for, interpreting, and favoring information in a way that confirms or supports an nondisabled (or ableist) perspective of disability. It is important that researchers with disabilities, in particular those with acquired disabilities, are encouraged to leverage their unique perspectives to explore the experience of adaptation and living with disability.

Each model also appears to adopt a different approach to adaptation, but in general, many view adaptation as a subjective and multidimensional process. All of the models recognize that significant variation exists both within and across individuals who go through the adaptation process. This suggests the importance of the individual's subjective analysis of their

circumstances in guiding their response to disability. The models also recognize that the onset of acquired disability may affect a wide range of physical, psychological, environmental, and social domains. As such, there are many domains that the individual must consider in response to acquired disability.

Another commonality across the literature is to characterize disability as a problem to react to, an intrusion, or disruption capable of bringing about chronic sorrow. The unified model, in particular, only conceptualizes negative cognitive and/or emotional reactions as elements of an individual's initial realization of acquired disability (Livneh, 1986). This negative framing suggests that acquired disability is a problem to be overcome. The models fail to consider any potential positive aspects of disability, such as how it can create possibilities, lead to joy, or allow an individual to be more than they were before becoming disabled. The apparent negative philosophical view of disability affects the conceptualization of each model development. Rather than recognizing the potential benefits or positives of disability, the models that explain the adaptation process perceive disability as merely a deficit that needs to be remedied. Thus, by default, the adaptation models assume that a successful outcome of the adaptation process can be described as a return to normalcy – the status quo. The models do not appear to consider possible adaptation for growth. Post-traumatic growth is the phenomenon of "positive change following the experience of trauma and adversity" (Hefferon et al., 2008, p. 32). In coping with a traumatic event, the individual may perceive benefits and experience personal growth. According to Tedeschi and Calhoun (2004), post-traumatic growth is "most likely a consequence of attempts at psychological survival, and it can coexist with the residual distress of the trauma" (p. 5). This means that individuals coping with a traumatic

event, such as an acquired disability, may experience negative and positive affective states at the same time.

Another point of contention in the literature is how individuals with a disability arrive at successful adaptation. The unified model argues that adaptation is a dynamic process in which people traverse through a linear series of stages in coming to terms with the disability. It takes an exclusively individual psychological approach to adaptation. The integrated model argues that people navigate periods of acceptance and chronic sorrow as they encounter each experience. It considers both the psychological and the socio-environmental influences on schema modification. The ecological models (i.e., Livneh's model, illness intrusiveness model, disability centrality model) argue for a quasilinear process of psychosocial adaptation that depends on the interaction between the individual and their coping resources, aspects of the disability, and the environment (Trieschmann, 1988; Vash & Crewe, 2003). The ecological models also consider the impact of disability on a range of life domains. The majority of models appear to indicate the importance of the environment in psychosocial adaptation to acquired disability as well as the interplay between the individual and the environment.

Historically, there has been a controversy about whether individuals who acquired a disability eventually experience a final adaptation outcome or continue to adapt to disability throughout their lives (Livneh, 1991; Vash & Crewe, 2003). The unified model argues that people reach a final stage of adjustment, while the integrated model rebuts that people never reach a final outcome. The ecological models argue for a summative outcome assessment based on various quality of life domains. Although the ecological models do not go as far as to claim a final stage of adjustment per se, they are constructed in quasilinear sequences to

quality of life outcomes. Despite the disagreement among researchers, it appears that there is some similarity in how the models conceptualize the adaptation process. The unified model makes the caveat that there is a possibility for regressing to an earlier stage when setbacks occur, and individuals may never reach final adjustment. This is not dissimilar to the concept of chronic sorrow incorporated in the integrated model.

A majority of the models were developed by integrating existing knowledge (Bishop, 2005; Kendall & Buys, 1998; Livneh, 1986, 2001) rather than through empirical study (Devins, 1983). Given the lack of empirical foundation for the models, more empirical research must be carried out to test the validity and applicability of each model and find support for the posited conceptualizations of adaptation to acquired disability. Only the illness intrusiveness model and the disability centrality model have seen empirical evidence that supports the model components in full. Meanwhile, limited research has found support for parts of the unified model and Livneh's model, and there has been nearly no research to evaluate the integrated model. The limited amount of studies found to evaluate the majority of the models (Bishop, 2005; Kendall & Buys, 1998; Livneh, 1986, 2001) suggests an area of research in need of further study.

The theoretical and empirical evidence to date suggests that *living with disability* is a subjective, multidimensional process of adapting to both disability and the environment. The onset of acquired disability triggers a period of psychosocial disequilibrium that appears to stabilize over time through the interaction of the individual, aspects of the disability, and the environment. The various models illustrate the different conceptualizations that can be created. The wide range of components that comprise each model demonstrates the difference

in importance given to factors by each author. While there are several models, the limited empirical research suggests the need for further study. Additionally, while some models have seen support from studies that utilize samples of individuals with SCI, there is a general lack of research to test the applicability of the models with people with SCI. Furthermore, no research has used any of the models to explore *living with disability* with a sample of athletes with SCI. This represents a gap in the literature and a large gap in our understanding of what it means to live with disability. The key problems with present conceptualizations of *living with disability* are that they are not founded on empirical study or with disabled perspectives, nor do they consider the positive aspects of disability in adaptation. Additionally, there is limited research exploring this field, particularly as it relates to women athletes who have acquired a SCI.

3.4. Chapter Summary

This literature review aimed to explicate the need to explore the psychosocial adaptation to acquired disability of women athletes after SCI and their stories of having a disabled body, being disabled, and living with acquired disability. This review presented and discussed the most prominent models developed to explain the three foci areas of this research. For each of the foci areas of research, concept definitions were presented to the reader. To *have a disability* means to hold, possess, or be able to make use of one's impaired body as one navigates the world, as well as the effects of impairment and disablism. To *be disabled* means to believe disability has become part of one's identity and a way of connecting to the disability community. To *live with disability* means to come to terms with, or put up with, being in a constant state of adaptation to that which is in front of them. These definitions reflect the current state of the literature within each foci area.

After reviewing the existing theoretical and empirical literature on having, being, and living with a disability, collectively, this is what is known. The majority of the models illustrate the importance of both internal and external factors as well as the interplay between the individual and their social environment (e.g., SRM, ICF, integrated model, Livneh's model, illness intrusiveness model, disability centrality model). This indicates that future investigations should consider both the internal and external influences on the disability experience. Many of the models also indicate that having a, being, and living with disability are malleable, changing concepts (Bishop, 2005a, b; Caldwell, 2011; Forber-Pratt & Zape, 2017; Gibson, 2006; Gill, 1997; Kendall & Buys, 1998; Livneh, 1986, 2001; Thomas, 1999; WHO, 2001). This means that conceptualizing each of the constructs requires the understanding that each individual's experience of disability may be in a constant state of change.

Several of the models indicate that there is significant variation both within and across individuals experiencing adaptation to acquired disability (e.g., unified model, integrated model, Livneh's model, illness intrusiveness model, disability centrality model). Despite the acknowledgment of individual differences in adaptation to acquired disability, few models consider the subjective nature of the individual's experience of disability to be essential to the conceptualization of having a, being, and living with disability (i.e., SRM, integrated model, disability centrality model). These models assert that the individual's experience of disability cannot be predicted by an objective analysis of the features of the person or the environment. Instead, the models indicate the individual's subjective analysis of *having a disability, being disabled,* and *living with disability* to be most important to understanding the individual's disability experience. Dunn and Burcaw (2013), in particular, highlighted the need to further

explore personal meaning as it relates to disability identity. Future research must consider the meaning individuals assign to their subjective experience of the three constructs.

What has become apparent throughout this review is there is little consensus on what it means to have a disability, be disabled, or live with disability. Each model seems to illustrate considerably different elements of the disability experience. This may be a result of how the models were developed and whom the models were developed by. A majority of the models across the three foci areas are rooted in a philosophy that considers disability to be a problem or deviation from the norm that needs to be fixed. The models discussed in regard to *having a disability* and *living with disability* fail to capture positive aspects of the disability experience. There is a lack of consideration for how disability may lead to growth, possibility, or joy (see Chun & Lee, 2008; Cole, 2004; Dunn, 1994). As a result, existing models appear to be limited in what they portray – not fully capturing the disability experience. To remedy this gap in the literature, it is important to explore stories of people with acquired disabilities. In a study of the characteristics of post-traumatic growth for people with SCI, Chun and Lee (2008) found participants were able to successfully re-story their lives following SCI to alternative stories that feature a renewed sense of personal agency and fulfillment (p. 11). Understanding the narratives that help people make sense of their circumstances may reveal positive aspects of psychosocial adaptation to acquired disability.

There is a noticeable difference in author characteristics across the models, which suggests the importance of holding an insider/outsider perspective in developing conceptualizations of having a, being, and living with disability. The majority of models included in the *having a disability* foci with identifiable authors are developed by disabled people (i.e.,

North American model, UK model, SRM). In the *being disabled* foci, the majority of models are developed by people with disabilities (Dunn & Burcaw, 2013; Forber-Pratt & Zape, 2017; Gibson, 2006; Gill, 1997). In the *living with disability* foci, all models are developed by nondisabled authors. The differences in author characteristics may have important consequences for model development. An insider perspective may provide access to valuable knowledge as well as a point of view that is different from an nondisabled person (Dembo, 1964; Brown, 2010; Wright, 1960). This perspective can not only enrich research but also change the approach taken by the researcher (Brown, 2010). Disabled people must have the power and opportunity to conduct disability research so that they may examine and capture relevant and important aspects of the disability experience.

This review also indicates that empirical research concerning what it means to have a disability, be disabled, and live with disability is limited. Few of the models have been evaluated in their entirety. There are a small number of studies that have utilized the models to examine these phenomena in people with SCI. Even fewer studies in the field of sport psychology or psychology of injury have engaged with the discussed models. Across all three foci, only two studies have utilized one of the discussed models with men athletes who have acquired a SCI (i.e., SRM; Smith, 2013a, b). In the literature, no research has utilized a model from the three foci with women athletes who have acquired a SCI. There has also been limited research that considers the individual's subjective experience of these phenomena (e.g., Haslett et al., 2017; Richardson et al., 2017). The lack of, or nonexistent, empirical support for many of the conceptualizations of the three foci put forth in the literature makes it challenging to believe in the reliability, truth, or strength of the models.

Based on this synthesis of the theoretical and empirical literature presented herein, there is a need to study the subjective, multidimensional experience of psychosocial adaptation to acquired disability as a result of SCI, particularly in women athletes who have acquired a SCI. By adopting a person-centered approach, there is a need to give voice to people with disabilities to speak to their lived experiences. As suggested by Dunn and Burcaw (2013), an inductive narrative approach should be utilized to understand stories of disability. This approach may allow the proposed research to capture the elements that comprise *having a disability, being disabled,* and *living with disability*.

Chapter IV: Methodology

The aim of Chapter IV is to outline the philosophical assumptions that guide this dissertation. Impelled by the literature reviewed in Chapter III, and consistent with the purpose and aims stated in Chapter I, this chapter will present the paradigm of the proposed research. A research paradigm is a set of philosophical assumptions that represent the researcher's conception of the nature of the world, their place in it, and the possible relationships to the world and its parts (Guba & Lincoln, 1994, p. 107). It consists of the researcher's ontological and epistemological beliefs about how a phenomenon should be understood. These philosophical assumptions inform the methodology used to acquire knowledge of the phenomenon. This qualitative project is framed by an interpretivist research paradigm. This paradigm endeavors to understand the individual and their culturally derived and historically situated interpretation of the social world (Crotty, 1998, p. 67). First, this chapter will introduce the ontology and epistemology of the research paradigm. Second, the methodology of the proposed research, including narrative inquiry (Riessman, 2008) and Photovoice (Wang & Burris, 1997) will be presented.

4.1. Ontology

Ontology refers to an individual's philosophical assumptions about the nature of being, the nature of the world, and what constitutes a reality (Crotty, 1998, p. 10; Denzin & Lincoln, 2005, p. 22). It is about identifying the nature of existence of the phenomenon being studied. The researcher takes a position on how they perceive things really are. The literature presented in Chapter III highlights the significant variation both within and between individuals experiencing adaptation to acquired disability. A few models (i.e., SRM, integrated model,

disability centrality model) in particular emphasized the importance of understanding the individual's subjective experience of acquired disability. This literature supports an ontological assumption that the nature of being disabled, of living in a world with disability, and what constitutes the reality of having a disability is subjective and constructed by individuals with acquired disability. Based on the literature reviewed, this research is underpinned by ontological relativism. Relativism is the view that reality is multiple, subjective, and socially constructed (Guba & Lincoln, 1994, p. 110). There exist as many realities as there are individuals. In effect, what we know about reality is foundationally shaped by the mind.

4.2. Epistemology

Epistemology refers to an individual's philosophical assumptions about the relationship between the researcher and what can be known (Denzin & Lincoln, 2005, p. 22). It is about how an individual understands knowledge, how they can know reality and communicate it to others, and the process by which knowledge is created, acquired, and validated (Guba & Lincoln, 1994, p. 108). The researcher takes a position on what it means to know. The literature presented in Chapter III suggests that both the disabled researcher and participants with disabilities bring important individual subjectivity to the creation of knowledge related to having a, being, and living with disability. This supports an epistemological assumption of the co-construction of knowledge and truth. Based on the literature reviewed, this research is underpinned by epistemological constructionism. Constructionism is the belief that knowledge is dependent on the subjectivities of the researcher and the participant, their backgrounds, and values. Knowledge is constructed through human perception and interactions between the individual and their social and cultural environment (Sparkes & Smith, 2014).

4.3. Methodology

Methodology refers to the way the researcher acquires knowledge of the world (Denzin & Lincoln, 2005, p. 22). It is the strategy or plan linking the researcher's choice of methods to the desired outcomes (Crotty, 1998, p. 3). Thus, it "is concerned with the why, what, from where, when, and how data is collected and analyzed" (Scotland, 2012). The researcher chooses how they go about finding out what they believe can be known (Guba & Lincoln, 1994, p. 108). The literature reviewed in Chapter III suggests a paucity of empirical evidence in the having, being, and living literature to support contemporary conceptualizations. This gap in the research warrants qualitative inquiry. This research adopts a mixed methodological qualitative approach that consists of narrative inquiry (Riessman, 2008) and Photovoice (Wang & Burris, 1997).

4.3.1. Narrative Inquiry

The chosen methodology to achieve aim 1 is narrative inquiry (Riessman, 2008). The narrative approach is a research methodology that directs inquiry at narratives of human experience (Hoshmand, 2005). It assumes humans live storied lives (Sarbin, 1986) and, to make sense of our experiences (e.g., injury, disability), we must construct and share narratives (Douglas & Carless, 2006). Narratives are how we meaningfully connect events in a clear sequential order for a specific audience (Esin, 2011). Analysis of the narrative aspects of stories can make known how the sociocultural landscape one lives in both shapes and is actively shaped by the individual (Smith & Sparkes, 2020).

Smith and Sparkes (2009) outline several basic assumptions of narrative inquiry that fit well with the constructs of having, being, and living with disability, of which three are

highlighted below. First, “narrative inquiry assumes that the body is a storyteller, and narratives are embodied” (Smith & Sparkes, 2009, p. 4). As such, *having a disabled body* can be understood through the stories the body tells. Second, “selves and identities are formed through narratives” (Smith & Sparkes, 2009, p. 4). As a consequence, what it means to *be disabled* is a product of narrative construction. Third, “meaning is created through narrative, and is a storied effort and achievement” (Smith & Sparkes, 2009, p. 4). This means that, in *living with disability* after SCI, a person draws on narrative to make sense of their experience. With few narratives to make use of, individuals may fall into meaningless existence (see Smith & Sparkes, 2008). By sharing narratives, an individual can re-create meaning and live a meaningful life with disability.

The literature in Chapter III suggests the disability experience is both personal and influenced by our environmental, social, and cultural world. This warrants the use of narrative inquiry to understand the narratives that comprise an individual’s personal story of disability and how society and culture influence the narratives available to constitute their story. Dunn and Burcaw (2013) suggested the use of an inductive narrative approach would help facilitate a wider understanding of disability, specifically, what it means to be disabled. The narrative approach does make it possible to gather data with more in-depth meaning as individuals are said to reveal themselves in their stories (Savin-Baden & Niekerk, 2007). The narrative inquiry methodology will enable the exploration of disability narratives among women athletes who have acquired a SCI and the documentation of the meanings they attribute to experiences of psychosocial adaptation to disability.

This research takes a constructionist narrative approach that views narrative as theme. As such, this approach explores “how meaning is constructed in narratives in relation to available cultural, social, and interpersonal resources” (Squire et al., 2014, p. 11). As this research aims to capture both the aspects of content and structure of narratives, a dual-narrative approach will consist of both the thematic narrative model and the structural narrative model. Adopting the thematic model of narrative analysis (Riessman, 2008), this research focuses on the content of narratives, and the themes around which a narrative is told. That is, what is said rather than how it is said (Riessman, 2008, p. 54). Adopting the structural model of narrative analysis (Riessman, 2008), this research also focuses on the telling of the story – how the narrative is formed and how elements of the narrative structure function.

4.3.2. Photovoice

Photovoice (Wang & Burris, 1997) is the chosen methodology to achieve aim 2. Photovoice is a photo-elicitation research methodology whereby members of a community are given cameras and asked to take pictures of events, people, or objects from their everyday life that represent aspects of their lives and communities (Wang, 1999). They then reflect and discuss the contents of the images in interviews with the researcher and in writings. Kirova and Emme (2006) argue that many elements that constitute one’s lived experience are not easily expressed or interpreted through the traditional qualitative research medium of the spoken or written word or narrative. Van Manen (1997) refers to the void of understanding created by spoken language itself as “epistemological silence.” A visual image such as a photograph can be used to create deeper meanings of the world as it can encourage participants to reflexively think, recall, and represent thoughts, feelings, and events captured in a moment (Glaw et al.,

2017; Raggl & Schratz, 2004). Photovoice's use of visual images as a research tool enables this research to achieve a deeper understanding of the three constructs than through narrative alone.

A strength of Photovoice is the dialogical conversation between the researcher and the participant. This conversation enables both to put forward their interpretations of the phenomenon captured in each photograph and, through this process, achieve a deeper understanding of the participant's experience (Plunkett et al., 2013). The literature in Chapter III highlighted the importance of the subjectivity of both the researcher and the participant in conceptualizing each construct. Photovoice promotes the co-construction of meaning through the dialogical interpretation process.

Photovoice creates opportunities for marginalized voices to capture data that is most meaningful to them (Plunkett et al., 2013). Participants are given the power to decide what and how to express their thoughts and feelings (Asaba et al., 2014). Photovoice is grounded in the belief that marginalized individuals, such as those with disabilities, are experts on their disability and in the best position to prioritize issues important to them (Lal et al., 2012). This methodology facilitates the achievement of aim 2 by providing disabled women athletes who have acquired a SCI the means to exercise their visual voice in capturing elements that shape their everyday life experience of having, being, and living with disability in the community. Few published studies have made use of Photovoice with a SCI sample (Lal et al., 2012). The studies (e.g., Newman, 2010; Newman et al., 2009) that have examined individuals with SCI have demonstrated the usefulness of Photovoice for obtaining insights about individuals with SCI and their experiences.

The literature in Chapter III suggests contemporary literature concerning disability is rooted in a philosophy that considers disability to be a problem, a weakness, and/or a deviation from the norm to be remedied. The main goal of Photovoice is “to enable people to record and reflect their community’s strengths and concerns” (Wang & Burris, 1997, p. 369). This methodology enables disabled people to represent their perceived psychosocial experiences with disability that may not reflect the philosophy underlining the existing literature.

4.3.3. Sample Size Determination

Neither narrative inquiry nor Photovoice abide by rules for the determination of minimum/maximum sample size. While no set justification for sample size exists for the proposed research design, a rationale can be gleaned from the published literature that have used narrative inquiry or Photovoice with physically disabled populations. A recent Google Scholar search of peer-reviewed, scholarly articles identified only 15 articles using narrative analysis with a physically disabled population (population M = 8.87, Mdn = 6, range = 1 – 30) and only 14 articles using Photovoice with a physically disabled population (population M = 7.71, Mdn = 7.5, range = 4 – 13). In the absence of clear recommendations, an appropriate sample size in relation to the research design can be found at the middle point (i.e., 8.29) of existing published research. As such, a purposive sample of 8 participants will be sought for this research, however, the final number of participants will be determined by saturation. Participants recruited for Study 1 will continue to Study 2.

Saturation is understood to be the point during data analysis when little or no new information is found relative to the study aim(s) from incoming data points (interviews), and when it is no longer feasible to conduct further coding (Fusch & Ness, 2015; Guest et al., 2020).

Given the types of data analyses (see 5.6.1.) proposed for this research, thematic coding will be used in both studies, and the Guest and colleagues (2020) method for determining thematic saturation in qualitative research will be employed. This approach includes three primary elements: (a) base size, (b) run length, and (c) new information threshold. Research indicates that most new information found in a qualitative study is generated early in the process (Guest et al., 2006). Consistent with the recommendations by Guest et al. and the sample size of this research, the base size will be set at four, run length at two, and the new information threshold at ≤ 5% new information.

Chapter V: Pilot Study

5.1. Introduction

A pilot study is a small-scale version of a planned research project designed to test and evaluate the need to modify research protocols, including data collection instruments and sample recruitment strategies, with a small sample of participants similar to those recruited for the larger research project (Doody & Doody, 2015; Jariath et al., 2000; Prescott & Soeken, 1989; van Teijlingen & Hundley, 2002). According to van Teijlingen and Hundley (2001), a pilot study is a crucial part of a research design that can serve three core functions: (a) to assess and refine research protocols (e.g., data collection instruments and recruitment strategies; Hundley & van Teijlingen, 2002; Kim, 2010; Sampson, 2004; Secomb & Smith, 2011), (b) to build researcher expertise in using the planned data collection and analysis techniques (Pratt & Yezierski, 2018), and (c) to detect ethical and practical issues that would hamper the larger research project (Kelly, 2007; Lancaster et al., 2004; Sampson, 2004). The purpose of the pilot study was to (a) assess and refine the research protocols, (b) enhance the researcher's expertise in using the data collection techniques and interview skills, and (c) identify ethical and practical issues.

5.2. Methods

5.2.1. Design

Consistent with the overall design of the research, the pilot study research design was qualitative, exploratory, sequential, and mixed methods (Creswell & Clark, 2017) using narrative inquiry (Riessman, 2008) and Photovoice (Wang & Burris, 1997) research approaches.

5.2.2. Participants

Most qualitative studies across various subject areas use 1–3 pilot participants (e.g., Majid et al., 2017; Mathieu-Soucy et al., 2018; Monson et al., 2021; Wu, 2020). Three participants were recruited for this pilot study. The participants were self-identified women who acquired a SCI and, as a result, have a physical disability (N = 3 Women, M_{age} = 52.67 years, SD = 11.68, age range = 40–63 years, $M_{age\ at\ injury}$ = 18 years, SD = 2, age at injury range = 16–20). The three women in this study were all self-identified athletes who had participated in sport for several years (M = 12.33, SD = 3.79, range = 8–15) before their respective SCIs.

5.2.3. Instruments

The pilot study employed the following data collection instruments: (a) eligibility survey (see Appendix A), (b) demographics survey (see Appendix B), (c) semi-structured interview guide 1 (see Appendix C), (d) field notes, (e) cameras, (f) photograph guidance (see Appendix D), (g) electronic logbooks, and (h) semi-structured interview guide 2 (see Appendix E). To gain insights from participants on the research instruments, the pilot study utilized a feedback questionnaire (see Appendix F).

5.2.4. Procedures

5.2.4.1. Recruitment. Individuals were recruited using a pilot study email invitation (see Appendix G) distributed through a collaborating site listserv (i.e., Minnesota Regional Spinal Cord Injury Model System). Individuals interested in participating in the pilot study completed the eligibility survey. Using the initial contact script, the researcher contacted those eligible to participate via email to schedule a one-on-one online interview via Microsoft TEAMS. The email included a URL link to the electronic informed consent form on Qualtrics.

Eligible participants for the pilot study met the inclusion and exclusion criteria: (a) self-identified as women, (b) were at least 18 years old, (c) lived within the United States, (d) acquired a disability from SCI, (e) participated in sport at the time of injury, and (f) were at least two years removed from the date of injury. Participants were excluded if they (a) did not speak English, (b) did not acquire a disability as a result of SCI, (c) acquired a SCI within the last two years, (d) had a pre-existing diagnosed disability prior to SCI, or (e) had a diagnosable psychological disorder or psychiatric impairment.

5.2.4.2. Data Collection. Participants in the pilot study completed the data collection procedures described in Study 1 and Study 2. Following the conclusion of the data collection, the researcher assessed the appropriateness of the recruitment materials and the semi-structured interview guides for both Study 1 and Study 2, determining whether these research instruments fulfilled the research objectives. The researcher adopted a posture of indwelling (Maykut & Morehouse, 1994), defined as "being at one with the persons under investigation, walking a mile in the other person's shoes, or understanding the person's point of view from an empathic rather than a sympathetic position" (p. 25). This involved listening and re-listening to interview recordings multiple times to immerse oneself in the data and strive to understand the participant's perspective from an empathetic rather than sympathetic position. This process of indwelling and reflection enabled the researcher to recognize how their preconceptions and biases influenced the data collection process. The researcher regularly participated in reflexive meetings with their supervisor to discuss participant feedback and analyze the effectiveness of the interview guides in collecting data relevant to the research questions of Study 1 and Study 2. Through this process, they assessed whether each content area (e.g., having, being, living

with disability, women's experience with disability, sport) was adequately covered, whether modifications were needed for the data collection protocol and interview questions, and whether the researcher was prepared to conduct qualitative interviews and proceed with the larger research project.

4.2.4.3. Feedback Collection. The researcher used the feedback questionnaire to gather insights from participants at various stages of the data collection process. Before the initial interview, the researcher sought feedback on the recruitment materials, which included a few brief questions about the comprehensibility of the informed consent form and the relevance and accuracy of the survey questions. After each interview, participants were asked for feedback regarding the quality of the interview questions, the researcher's conduct during the interviews, and whether additional questions could have provided insights into issues pertinent to the research questions. After the second interview, participants were questioned about the Photovoice data collection procedures to gather feedback on the photo-taking process. Participant feedback was collected through discussion.

5.3. Outcomes

Based on the pilot study, the following changes were made to refine research protocols, ensure researcher readiness to execute the research effectively, and address identified ethical and practical issues that would hamper the larger research project.

5.3.1. Research Protocols

The pilot study revealed that the recruitment materials were not ideally designed to assess participant eligibility. Based on participant feedback and the researcher's experiences with these materials, the researcher revised the eligibility survey to improve clarity and ensure

that all data collected specifically pertains to the eligibility criteria. Questions not directly related to eligibility were removed and will instead be asked after participants provide consent using the demographics survey (see Appendix B). The demographics survey will collect data about the participant's demographic information, injury, sport participation, and camera preference before the Study 1 semi-structured interview. Furthermore, considering the changes made to the data collection materials and procedures, the Email Invitation, Informed Consent Form, and various contact scripts were updated to better reflect the research protocol.

Based on conversations with their supervisor, the researcher made initial modifications to the interview guides to ensure they adequately covered each content area (e.g., having, being, living with disability, women’s experience with disability, sport). From the interviews, it was observed that participants occasionally struggled to come up with stories to share. Feedback from participants suggested that pre-interview prompts would better prepare for the interview and have stories ready for discussion. The researcher included pre-interview prompts in the email that would be sent to participants prior to the Study 1 interview. Participant feedback also indicated that the interview guides were neither comprehensive nor organized in a way that effectively facilitated storytelling. After evaluating the effectiveness of the interview guides in collecting pilot data relevant to the research questions of each study, the researcher revised the interview guide questions to improve clarity, reduce redundancy, and better enable participants to share their experiences. The researcher added, modified, and rearranged interview questions to promote coherent storytelling and discussion on the three research foci. Additionally, the researcher included prompts to assist participants as they narrate their stories.

Based on observations from the pilot study interviews, the researcher evaluated and determined the necessary amount of time to complete the interviews for each respective study. It was concluded that approximately 120 minutes would be required to finish the Study 1 semi-structured interview, and considering the pacing and the number of questions per photo, approximately 90 minutes would be required to complete the Study 2 photo-sharing interview.

Following discussions with their supervisor about whether the photograph guidance would ensure participants collect data pertinent to the research questions of Study 2 and sufficiently address the relevant content areas, the researcher revised the photograph guidance to include two additional themes: (a) what it means to be a woman with a disability, and (b) what it means to be a woman athlete after SCI. Furthermore, following observations from the photo-sharing interviews, it became evident that participants needed instruction to ensure they captured enough photos to address the relevant content areas. The researcher added the requirement for participants to capture at least one photo for each theme to guarantee that all themes were represented in their photo-taking. Participants were also instructed to associate each photo with a theme in their electronic logbook, ensuring easy reference during the interview and that the chosen theme remains consistent between capture and interview.

5.3.2. Researcher Readiness

After regular reflective discussions throughout the pilot study about what was needed to conduct the research and based on the experiences of implementing the research protocol with the three pilot participants, the researcher and their supervisor concluded that the researcher was ready and capable of executing the larger research project effectively. The researcher’s past and pilot study experience in conducting qualitative interviews enabled them

to develop valuable skills and techniques, including managing the interview pace, utilizing the interview guide effectively, asking probing questions for additional insights, and enhancing participant engagement.

5.3.3. Ethical and Practical Issues

Pilot participants noted that using disposable cameras presented significant challenges when taking photos. The participants reported that it would have been easier for them to capture images with their personal devices because (a) they always have their personal devices with them, while they often forgot to bring a disposable camera; (b) they could review the photos they took on their personal devices, whereas they struggled to match images with their logbook since they could not easily check the disposable camera photos; and (c) they felt more comfortable and in control when using their personal devices. Based on the feedback, it was decided that participants could choose between a disposable camera or their personal device for Study 2 data collection. The limit of 27 photographs was kept to ensure consistency between the two camera options.

The pilot participants reported having difficulty capturing images that excluded other people's faces. In fact, many of the images they shared would lose their meaning without the presence of others. Based on the feedback, it was determined that participants would be allowed to take photographs that include others. By photographing another person, that individual would now be considered a research subject as well. Therefore, an online Subject Consent Form (see Appendix H), accessible through Qualtrics, along with instructions on when and how to use the consent form and guidelines for photographing others, were included in the photograph guidance provided to participants.

Chapter VI: Study One

6.1. Abstract

Current research on women athletes' experiences of psychosocial adaptation following spinal cord injury (SCI) is notably limited, as highlighted by a recent systematic review (Zike et al., 2024). This research gap is significant, given that women encounter distinct societal challenges at the intersection of disability, gender, and sport, which deeply influence their daily lives as they adapt to acquired disability. This study explored the disability narratives of women athletes after SCI and documented the meanings attributed to experiences of psychosocial adaptation to acquired disability, particularly what it means to have a disability, be disabled, and live with disability. Using a qualitative, exploratory, narrative inquiry (Riessman, 2008) approach, nine women athletes with an acquired disability as a result of SCI completed a virtual, semi-structured interview. The data were analyzed using an iterative, inductive, dual-narrative process consisting of both categorical-content analysis and structural analysis (Lieblich et al., 1998). A total of four narrative types were identified: *Attachment to a Nondisabled Past*, *Push for Recovery*, *Embracing Life Without Embracing Disability*, and *Transformation Through Shared Experience*. The four narrative types illustrate the unique challenges faced by women athletes after SCI, as having a disability affected their experiences of womanhood and athletic identity. The narratives also characterized *having a disability* as embodying disability stigma and being social-relational in nature while highlighting the autonomous agency in *living with disability*. Furthermore, the narratives demonstrate how *being disabled* and *living with disability* are constructed in relation to both disabled and nondisabled individuals. The findings underscore the collective nature of the acquired disability experience, while also emphasizing

the uniqueness of each woman's personal narrative. By illustrating the connections between *having a disability*, *being disabled*, and *living with disability*, the study emphasizes the importance of understanding these connections in investigating psychosocial adaptation to acquired disability.

6.2. Introduction

Disability is defined as any condition of the body or mind that makes it more difficult for the person to do certain activities and interact with the world around them (Centers for Disease Control and Prevention, 2022). Understanding of disability has evolved over time, leading to a variety of conceptualizations that consider the disability experience as either an individual tragedy to overcome (Campbell, 2009; Loja et al., 2013; Oliver, 1996), a result of societal barriers that limit participation (Darcy & Buhalis, 2011), or a type of social oppression that manifests through relationships as individuals with impairments interact with social structure and social agency (Thomas, 1999, 2007). Common across the above conceptualizations is a philosophy that views disability as a problem, a weakness, or a deviation from the norm that needs to be remedied (e.g., Oliver, 1990; Thomas, 1999; WHO, 2001). Ableism, the dominant disability narrative in Western society (Ahlvik-Harju, 2016), is "a network of beliefs, processes, and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human" (Campbell, 2001, p. 44). Those who deviate from this standard are often viewed as disabled (Campbell, 2009).

Women with disabilities face unique challenges due to the intersection of disability and gender. They deviate from societal standards of hegemonic masculinity and the ideal of femininity, which, according to Gill (2007), is primarily associated with physical attributes rather than social or psychological attributes. This disconnection from cultural standards creates a dilemma for women with disabilities, as noted by Garland-Thomson (2002), who states that they are considered "removed from the sphere of true womanhood and feminine beauty."

Research shows that cultural narratives portray women with disabilities as helpless, asexual, unsuitable for motherhood, and inadequate for traditional female roles (Fine & Asch, 1988; McDonald et al., 2007), undermining their status as women. This interplay between disability and gender raises significant psychosocial issues that women with disabilities must confront as they navigate society.

Compounded by the intersection of gender and disability, within the sports domain, women with disabilities face substantial challenges (DePauw, 1997). As a social institution, sport reflects and reinforces the dominant cultural norms, standards, and ideologies within society, creating unequal power relationships (Hall, 1997; Hargreaves, 1994; Jhally, 1989; Sage, 1990). Women – not just those with disability – in sport often face marginalization, stigmatization, and trivialization in their efforts to construct meaningful sport experiences (Blinde & McCallister, 1999; Kane, 1996). Research has shown that cultural narratives surrounding women in sports have often relied on stereotypes and gender bias instead of focusing on athletic performance (Krieger et al., 2022). Such narratives have limited women's involvement in sports and diminished their status.

Women in sport also navigate the tension between contrasting societal ideals of femininity and the ideal feminine body (e.g., thin, slender, absence of musculature; Grogan et al., 2004) and the ideal athletic performative body (e.g., muscular, strong, nondisabled; DePauw, 1997; Hardin et al., 2002). These dual forces pressure women athletes to conform to expectations of both femininity and masculine notions of muscularity necessary for athletic performance (Krane, 2001). This challenge is amplified for women athletes with acquired disabilities, as the disabled body—perceived as weak, passive, and dependent (DePauw,

1997)—often fails to meet the standards of the "ideal sporting body" (Hardin, 2003). Considering the challenges women athletes face at the intersection of sport, gender, and disability, it is important to understand how they construct meaningful experiences and shape their narratives of adapting to acquired disability.

A common acquired disability from sport is spinal cord injury (SCI). A SCI is a neurological condition usually caused by a sudden, traumatic impact that fractures and/or dislocates the spine, resulting in bruising, partial rupture, or complete severing of the spinal cord (Crewe & Krause, 2009). The abrupt onset of impairment and disability following SCI constitutes a psychosocial crisis that significantly disrupts an individual's life (Livneh & Antonak, 1997; Moos & Schaefer, 1984). Research on the psychosocial adaptation experiences of athletes who acquire a SCI is limited (Zike et al., 2024). Of the published research that exists, the lived experiences represented come largely from a homogenous sample of White men, and only five studies have included women. As a result, women athletes' lived experiences of psychosocial adaptation to acquired disability after SCI are not well understood.

To gain a better understanding of women athlete's psychosocial adaptation to acquired disability after SCI, this study focused on three specific aspects of women athletes' experiences of psychosocial adaptation to SCI and acquired disability: (1) *having a disability*, (2) *being disabled*, and (3) *living with disability*. For clarity, in this study, *having a disability* was conceptualized as the meaning assigned to possessing an impaired body as one navigates the world, *being disabled* was conceptualized as the meaning assigned to disability identity and the effect that has on the relationship with self, others, and environment, and *living with disability* was conceptualized as the meaning assigned to the process of adaptation to disability and the

factors affecting the process. This study aimed to explore the disability narratives of women athletes after SCI, and to document the meanings they attribute to experiences of psychosocial adaptation to acquired disability. To address this aim, this study sought to answer the following research questions:

1. What does it mean to women athletes who have acquired a SCI, in their experience of psychosocial adaptation to acquired disability, to have a disabled body in an ableist society?
2. What does it mean to women athletes who have acquired a SCI, in their experience of psychosocial adaptation to acquired disability, to be disabled in an ableist society?
3. What does it mean to women athletes who have acquired a SCI, in their experience of psychosocial adaptation to acquired disability, to live with disability in an ableist society?

6.3. Methods

6.3.1. Design

This study used a qualitative, exploratory, retrospective research design. The researcher collected qualitative data using a narrative inquiry (Riessman, 2008) research approach. Underpinned by an ontological belief that reality is multiple, subjective, and socially constructed (i.e., relativism; Guba & Lincoln, 1994, p. 110), and an epistemological belief that knowledge is constructed through human perception and interactions between the individual and their social and cultural environment (i.e., constructionism; Sparkes & Smith, 2014), the constructionist narrative approach was adopted. This approach enabled the researcher to

explore “how meaning is constructed in narratives in relation to available cultural, social, and interpersonal resources” (Squire et al., 2014, p. 11).

6.3.2. Positionality

The researcher is a disabled, white, cisgender man with a personal history of SCI, having acquired quadriplegia in late adolescence due to an ice hockey accident. This acquired disability served as the primary motivation for the research topic, allowing an insider’s perspective on the disability experience. This personal familiarity with participants’ experiences affected all aspects of the research process. The researcher's insights and personal experiences enhanced the study by informing its conceptualization, shaping the data collection methods and research instruments, and offering further perspective that facilitated the interpretation and analysis of participants’ accounts. Upon reflection, the researcher, who has a visible disability, often found that participants viewed them as an insider during the interviews. This perception enhanced feelings of familiarity, trust, and rapport, as participants frequently remarked that the researcher’s shared experience with SCI made them feel more comfortable sharing information they might not disclose to someone without an SCI.

6.3.3. Participants

Participants were self-identified women who acquired a SCI and, as a result, have a physical disability (N = 9 women, $M_{\text{age at injury}}$ = 28.33 years, SD = 12.56, age at injury range = 17–46). Five reported a complete SCI, while four reported an incomplete SCI. The women in this study were all self-identified athletes who had participated in sport for several years (M = 13.33, range = 7–22, SD = 4.47) before their respective SCIs. In this study, sport is defined as a (a) freely chosen, voluntary activity that is (b) governed by rules (i.e., constitutive rules, rules of

decency, and fair play), (c) physically challenging, and (d) involves competition in a mutual challenge to achieve excellence (Boxill, 2003). See Table 3 for participant demographics.

Table 3

Study One Participant Demographics

Participants	**Age**		**Level of SCI**	**Type of SCI**	**Completeness of SCI**	**Athletic Identity at SCI**	**Years in Sport Before SCI**	**Race**
	SCI	Interview						
Angela	42	52	C5/C6	Sport	Complete	Yes	22	White
Chelsea	17	19	L1	MVA	Incomplete	Yes	14	White
Eva	46	48	T9	Surgical	Incomplete	Yes	16	White
Gillian	24	28	C6	Medical	Incomplete	Yes	11	White
Iris	46	52	T5	Sport	Complete	Yes	15	White
Julia	24	27	T6	Sport	Complete	Yes	8	Native Hawaiian
Kendall	17	54	T11/T12	Fall	Complete	Yes	13	White
Laura	19	63	T7	Sport	Complete	Yes	7	White
Miranda	20	33	C5/C5	MVA	Incomplete	Yes	14	White

6.3.4. Instruments

6.3.4.1. Eligibility Survey. The eligibility survey (see Appendix A) was used to gather demographic data to identify individuals who met the inclusion and exclusion criteria, collect eligible participants' contact information, and obtain consent for the researcher to make initial email contact. The data were analyzed for consistency with inclusion and exclusion criteria, and those meeting these criteria were contacted about participation.

6.3.4.2. Demographics Survey. The demographics survey (see Appendix B) was used to collect data related to the participant's demographic information, injury, sport participation, and camera preference prior to the semi-structured interview.

6.3.4.3. Semi-Structured Interview Guide. A semi-structured interview guide (see Appendix C) was used as they allow participants freedom to discuss their stories and the experiences most important to them, but they also give the researcher opportunities to focus on specific areas of interest (Sparkes & Smith, 2014). The semi-structured interview guide was developed using knowledge gained from the literature review in Chapter III and the pilot study to ensure it touched upon aspects of having, being, and living with disability and the context in which the SCI occurred.

The interview guide began with questions that asked about the participant's life before and after the SCI (e.g., tell me about your injury). To encourage storytelling, participants were regularly prompted to share experiences with statements such as "Tell me a story about…" or "Tell me about a particular time when…" The majority of the interview guide consisted of primary questions structured around the three major constructs: (a) *having a disability*, (b) *being disabled*, and (c) *living with disability*. Examples of questions crafted to touch on the foci of the interview included "Tell me about your day-to-day life with a disability", "How has disability changed how you see yourself?", and "Tell me what having a disability means to you." The questions were open-ended, focusing questions that were framed in everyday language. This form of questions allows participants flexibility to tell their story rather than be directed at what to address (Smith, 1995). Follow-up questions or prompts were used to supplement the primary questions on the interview guide and elicit rich data, providing participants with

opportunities for explanation and elaboration (Sparkes & Smith, 2014). The interview guide concluded with a broad question, allowing participants to add anything they felt was relevant to their experience with disability or SCI.

6.3.4.4. Field Notes. The researcher used field notes (Patton, 2002) during data collection to document thoughts and self-reflections, and engage in reflexivity on aspects of the research (van Manen, 1997). This instrument assisted interpretation by preserving contextual information and immediate thoughts. The field notes were used both during and after the online semi-structured interview in this study.

6.3.5. Procedures

6.3.5.1. Recruitment. A collaboration email (see Appendix I) was sent to several sites (i.e., Wisconsin Adaptive Sport Association, Mount Sinai Spinal Cord Injury Model System, Minnesota Regional Spinal Cord Injury Model System, Texas Model Spinal Cord Injury System, University of Pittsburgh Model Center on Spinal Cord Injury, University of Alabama-Birmingham Spinal Cord Injury Model System, Rocky Mountain Regional Spinal Injury System, National Capital Spinal Cord Injury Model System, Spaulding New England Regional Spinal Cord Injury Center, Northern New Jersey Spinal Cord Injury System) to request assistance distributing recruitment materials for this study. The selected sites aided in sending out an email invitation (see Appendix J) that detailed the study, provided researcher contact information, and included a QR code directing individuals to the eligibility survey on Qualtrics. Those who met the eligibility criteria were contacted by the researcher via email using an initial contact script (see Appendix K) to arrange a one-on-one online video interview. This email contained a hyperlink to the electronic informed consent form (see Appendix L) on Qualtrics. Participants were informed

in both the email invitation and the electronic informed consent form about research compensation in the form of a $50 Visa gift card, which was sent via email using a conclusion script (see Appendix M) after the data collection process was completed.

Participants were recruited through purposive and snowball convenience sampling (Frost, 2021). Participants were included if they (a) self-identified as women, (b) were at least 18 years old, (c) lived within the United States, (d) acquired a disability from SCI, (e) participated in sport at the time of injury, and (f) were at least two years removed from the date of injury. Participants were excluded if they (a) did not speak English, (b) did not acquire a disability as a result of SCI, (c) acquired a SCI within the last two years, (d) had a pre-existing diagnosed disability prior to SCI, or (e) had a diagnosable psychological disorder or psychiatric impairment. There was no limit to eligibility based on years since SCI because, based on the literature, adaptation to disability is believed to be an ongoing process; therefore, time since injury was not believed to substantially affect recall when participants were still presently coming to terms with acquired disability.

6.3.5.2. Sample Size Determination. Based on published literature that has used narrative inquiry with physically disabled populations, a purposive sample of eight participants was sought for this study. However, the final number of participants was determined by saturation. Given the types of data analyses (see 6.3.6.) used in this study, the Guest and colleagues (2020) method for determining thematic saturation in qualitative research was employed. This approach includes three primary elements: (a) base size, (b) run length, and (c) new information threshold. Consistent with the recommendations by Guest et al. and the

sample size of this study, the base size was set at four, the run length at two, and the new information threshold at ≤ 5% new information.

After reviewing the individual interview data (IID) from the first four participants and summing the number of unique themes identified within this group, the resulting total was a base size of 20. Next, the number of unique themes was found for the first run (i.e., Participants 5 and 6), which totaled 6, resulting in a new information percentage of 30%. This did not meet the study's new information threshold. Subsequent runs two (25%) and three (15%) also did not meet the new information threshold. The fourth run yielded a new information percentage of 5%, which met the study's new information threshold; thus, no further data collection or coding was conducted (see Table 4).

Table 4

Thematic Saturation

Interview number	**1**	**2**	**3**	**4**	**5**	**6**	**7**	**8**	**9**
New themes per IID	8	4	4	4	3	3	2	1	0
New themes in run					6		5	3	1
% change over base						30%	25%	15%	5%

6.3.5.3. Data Collection. Semi-structured interview data were collected through virtual, one-on-one interviews with each participant through video call software (i.e., Microsoft Teams). The researcher listened attentively and used prompts to probe deeper if participants were not being expansive in their responses or to follow up on anticipated answers. The interviews ranged from 81 to 170 minutes, with an average interview time of 116 minutes (*SD* = 26.63). All interviews were audio and video recorded and transcribed using Glean® and

Microsoft TEAMS software. Each interview transcript was reviewed for accuracy, and the participants were assigned pseudonyms that they were referred to throughout the study. Any participant identifiers (e.g., names, locations) were replaced or removed from the data (i.e., transcripts, recordings, notes, photographs). The University of Wisconsin-Milwaukee Institutional Review Board approved this study.

6.3.6. Data Analysis

Using NVivo 14 (Lumivero, 2023), the data were analyzed using an iterative, inductive, dual-narrative analysis consisting of a categorical-content analysis and a structural analysis (Lieblich et al., 1998). The researcher employed analytical bracketing, a technique by which the researcher focused separately and exclusively on the content of stories (i.e., the *what's* of narrative) before moving to focus on structure (i.e., the *how's*/*why's* of narratives) and back again (Gubrium & Holstein, 2009; Smith & Sparkes, 2012). The researcher began with the categorical-content analysis, focusing on the *what's* of narratives. After the initial reading of the first group of four transcripts, the researcher coded transcripts line by line for content before proposing initial themes both individually and for the transcripts as a whole. After coding the first transcript, a master code list was constructed. As the researcher proceeded through the next transcripts, codes were either pulled from the master list, if applicable, or new codes were created and added to the master list. Codes were then placed into logical categories that reflected the themes that became apparent and represented the important aspects of the stories. During the categorical-content analysis, patterns that became apparent were temporarily bracketed, and the researcher made a note to return to the data later to more rigorously focus on the *how's* of the narrative. Following the initial categorical-content analysis

phase, the researcher analytically bracketed out any concerns for the *what's* of narratives and instead examined the *how's* of narratives through structural analysis.

During the structural analysis phase, transcripts were re-read and coded according to narrative structures. The researcher identified different narrative types and narrative structures, such as the narrative plot, available to participants to construct their stories. After the initial reading of the first group of four transcripts, the structures of the stories began to emerge. The remaining transcripts were examined for the same structures. However, the researcher remained open to alternative narrative structures. Each participant was assigned to a narrative type based on the key features of their stories. The researcher examined the key features of the narrative type groups that participants were assigned to. Once the structural analysis phase was finished, the researcher transitioned back to categorical-content analysis. In the second phase of categorical-content analysis, the researcher explored the key content expressed within each narrative type and compared the narrative types with the themes the researcher had constructed from the data.

6.3.7. Methodological Integrity

Strategies were employed to ensure trustworthiness and reflexivity. The researcher engaged in member-checking (Creswell & Miller, 2000) by sharing interview transcripts and the researcher's initial themes with participants and requesting them to reflect on the documents and provide feedback within two weeks. The researcher asked participants to think about the appropriateness and believability of the interpretations and offer critique or affirmative feedback (Smith & McGannon, 2018). This method helped to determine whether the data analysis was congruent with participants' experiences. The researcher also engaged in peer-

debriefing (Barber & Walczak, 2009), after member-checking was completed, by sharing interview transcripts and lists of initial themes with a critical friend. The critical friend reviewed the interview transcripts and lists of initial themes, questioned their construction, and explored alternative interpretive possibilities. Through dialogue with the critical friend, the researcher was able to determine whether a case was defendable and if the interpretations made were plausible (Smith & McGannon, 2018). The third author served as the critical friend. Field notes were kept throughout the study. A reflexive diary (Clancy, 2013) was one element of the notes taken. This provided an opportunity to document and reflect on thoughts and actions during study procedures to better understand how the researcher's perspective and experiences influenced the study. Throughout the study, the researcher and the second author met for reflective discussions of study procedures. These meetings encouraged self-reflection and discussion of aspects of the study.

6.4. Results

Following an iterative, inductive, dual-narrative analysis consisting of both categorical-content analysis and structural analysis (Lieblich et al., 1998), the study identified key themes and structures in the narratives shared by women athletes following SCI. A total of four narrative types were identified: *Attachment to a Nondisabled Past*, *Push for Recovery*, *Embracing Life Without Embracing Disability*, and *Transformation Through Shared Experience*. What follows is a brief description of each, followed by participant narratives.

6.4.1. Narrative One: Attachment to a Nondisabled Past

Two participants, Angela and Kendall, belonged to a narrative type *Attachment to a Nondisabled Past*, which refers to narratives characterized by stagnated progression due to an attachment to aspects of the nondisabled experience (i.e., roles, identities, embodiment).

6.4.1.1. Angela. Angela is a White woman living in California who was 52 years old at the time of the interview. She was 42 years old, an avid club cyclist and civil engineer, when she acquired a C5/C6 complete SCI when struck by a car while cycling. Angela's narrative tone was characterized by optimism about the future but also frustration and disappointment about her capabilities and opportunities. In rehabilitation, Angela accepted that she could not change what had happened and that she must learn to do things differently. She resolved to do everything she could to "make the most of it" by overcoming the challenge of SCI and what she perceived to be a "broken" body, choosing to move forward. While going through rehabilitation, Angela perceived that the care she received had a male-centric focus: "They had, uh, men and sexuality section, and I was the only woman. So, I actually go, 'So, do you have a women and sexuality?' And he goes 'No.' And I look at him and go, 'Well, shouldn't you?'" She believed that the rehabilitation professionals did not think that much about women because most people with SCI are men. Due to this perceived male-centric approach to care, she felt that the medical professionals questioned her emotional expression and interpreted it as indicative of "mental instability":

> She asks, 'So, when you're sad, what do you do?' I look and I go, 'I cry, and then I feel better.' The very thing that she's, you know, questioning me about, thinking that it's a sign of my mental instability. I actually see as my mental strength.

Through rehabilitation and multiple surgeries, including tendon transfer surgery, she was able to gain greater control over her body and maximize her capabilities. Nonetheless, she explained that she must remain attentive to her body's needs to navigate each day effectively, "I live and breathe by the timing of my bladder because I can't feel when I need to go. Uh, and if I'm not careful, I will leak, so I have to stay on top of that." Angela explained that to better manage her bladder care needs through intermittent catheterization, she had to have a suprapubic procedure, "So, this whole, you know, access through the belly button basically gives me the ability to do what men can do naturally." Since acquiring a SCI, Angela has regained considerable independence, although she continues to be frustrated by the need to rely on others to accomplish tasks that she could do herself before her SCI.

Despite her expressing, "Of course, I should be moving forward," Angela demonstrated an attachment to the identities, roles, and experiences she had before her injury. Motivated by a desire to have value, to meaningfully contribute so she could avoid becoming "a net drain on society," and to restore a sense of normalcy, Angela was determined to return to work before the end of the year of her injury. It was important to her to maintain her identity as a full-time working mom. To achieve this, she had to work through various challenges to figure out how to fulfill those roles by different means than she was used to. She also had to fight against the stereotypes about her capability to contribute at her worksite. Angela defied others who claimed, "You can't do that job because of all the stairs. You can't do that job because it's an industrial facility. You can't do that." Ultimately, she succeeded in making these adaptations and reclaiming her identity as a full-time working mom.

Motherhood was an important part of Angela's life before SCI. She initially found it difficult to accept how having a disability affected her as a mother because her SCI changed what she could provide: "I feel like I let my kids down a little bit." While she used to be a more hands-on mother (e.g., preparing meals, doing laundry), she explained that she has adapted to become "much more of an emotional champion." Angela believes that she has come to accept her limitations and focuses on finding ways to make things work:

> No, I can't run a vacuum, but I can plan meals. Umm, now I can't cook the meal, but I could set the table. You know, there are things I can do. So, learning, you know, those aspects where I can contribute. Umm, I used to do more before, but you know I do what I can now and then learning to accept that things aren't gonna be the way I want them to be.

Angela faced challenges in accepting the loss of her athletic abilities. She struggled to move beyond her previous identity as a cyclist and the athletic body she had developed through sport. She expressed her frustration with her disabled body, "I feel like it's let me down." Her engagement in sport before her SCI intertwined with many significant aspects of her life, such as health, fitness, social interactions, community, and family. This strong connection to her past sporting experiences and athletic body hindered her narrative development. Although she explored various adaptive sports after her injury, Angela believed none could match the satisfaction she derived from cycling: "It has to be so dang adapted that you miss the spirit of the sport… Does it maintain what it was or what it offered to me? No, it just doesn't." This belief prevented her from enjoying adaptive sports and physical activities such as going to the gym. She demonstrated fixed thinking when discussing why she would not

consider hand cycling, stating, “My arms aren’t the strong part of me. My legs were strong. That’s why cycling was so awesome. I don’t wanna handcycle. It’s not the same. I want to be back on a bicycle.” Ultimately, she withdrew from sports entirely and discarded her athletic identity due to her dissatisfaction with available sports and physical activities, but she remained tethered to her former nondisabled experiences.

Angela’s stated belief in moving forward does not align with her actions. She has struggled to move beyond her life before SCI and her attachment to her previous embodiment. In fact, she appeared to be holding on to what she had, preventing her from exploring alternative paths forward. This is reflected in her relationship with disability. Angela believed that disability carries negative connotations that lead to assumptions about what she cannot do. She refused to accept the disability “label” or identify with it because it challenged her ability to decide for herself. She stated that she has adapted to having a disability by pretending it does not exist, whether that means ignoring it or trying to downplay it. It was important to her to be seen for who she truly is. Angela said she often jokes that it does not matter what she wears or how she looks because people do not see her; they see the wheelchair. She mentioned that the best compliment she has received is when someone said they did not “see the wheelchair”; rather, they only saw her. This compliment was meaningful to her as it reinforced her self-concept. Despite her unwillingness to identify with disability, Angela did feel a responsibility to be an ambassador for people with disabilities to show nondisabled people that they are just people.

6.4.1.2. Kendall. Kendall is a White woman living in Vermont who was 54 years old at the time of the interview. She was 17 years old, an active athlete involved in multiple sports

(i.e., cycling, running, Nordic skiing), when she acquired a T11/T12 complete SCI from a fall from a tree. Kendall's narrative tone was characterized by a mix of resilience, frustration, and thoughtful introspection, revealing a complex process of overcoming both internalized and societal ableism. While undergoing rehabilitation, Kendall was focused on walking again. She wanted to maintain the lifestyle she had lived before the accident and regain as much of the capabilities she had beforehand as possible because, as she stated, "that was what I had known for 17 years of my life. That was normal for me." Though unable to regain the ability to walk, Kendall has attained a level of independence that enables her to live on her own and manage the realities of her disabled body (e.g., neurogenic bowel and bladder management, skin care, and pressure sore maintenance). Despite the independence she enjoys, Kendall acknowledged that her environment is not as accessible as it could be. However, she has observed significant advancements in accessibility over time, especially since the passage of the ADA, which has made activities like catheterization outside the home much easier than it once was: "There were a lot of kind of crazy moves I had to do to, like, get in and out of an inaccessible bathroom stall, for instance, you know, swinging across on the door, crawling underneath." She expressed how inaccessibility continues to affect her in her daily life, stating, "It's kind of an almost daily reminder of the fact that I'm not like everyone else, and that can be frustrating because you feel other, you feel outside. You feel not thought of. You feel, you know, disempowered."

Kendall was accustomed to being an athlete and drawing satisfaction from her nondisabled athletic body and sport performance before SCI. Acquiring a SCI disrupted her ability to pursue an anticipated elite athletic career, so she felt that being an athlete had been taken from her. Kendall avoided adaptive sport in the early years after her SCI.

> I think that a part of me still was kind of looking down on it a little bit, though. Like, this isn't real sport. I had almost a bias against myself, you know, and people like me. I still had this able-bodied mindset inside a disabled body. Yeah, I was kind of judging it or feeling like it was less than somehow.

While she explored alternatives such as art, she could not find a meaningful occupational pursuit that she was truly passionate about. Kendall came to believe that regaining an athletic pursuit via adaptive sport was important. She eventually returned to sport through hand-cycling, which she has come to embrace as her primary pursuit. Kendall continues to identify as an athlete, stating that she pursues sport with a "serious attitude" and invests time, focus, energy, and resources in training, traveling, competing, and refining her equipment. She emphasized that adaptive sport has been much more meaningful to her than it was to her as a nondisabled athlete, as it serves as "a necessary lifestyle habit" that helps her maintain her social connections as well as the strength and endurance of her disabled body. Despite achieving success in adaptive sport, she still did not consider it a genuine career and continued to feel occupationally aimless.

In addition to feeling like she was "spinning her wheels" in the occupational sphere of her life, Kendall also felt as though the relationship sphere was blasted to pieces on a psychic level. She had lost confidence in herself, and SCI disrupted her appreciation for her athletic body and its desirability.

> It's harder to love my body because of the way it looks. I mean, I do still love my body because it's my body, but I don't love the way it looks, and not only the way it looks, but the way you know it behaves or doesn't behave… It doesn't feel good. I get bloated a

> lot. You know, my tummy sticks out. I don't like that. Umm, you know, it's tough to deal with it… I still love it. It's me. It's part of me… I just, yeah. I'm not in love with it like I used to be when I was a teenager.

With a compounding relationship break-up after her SCI, Kendall developed deep insecurities about her disabled body that made her feel less desirable and inferior in comparison to nondisabled women. "It was always really super hard for me to feel confident with a guy and to feel like I was good enough or that, you know, I've felt too flawed and, like a burden and that sort of thing." This internalized ableism undermined her romantic relationships after SCI, making it difficult for her to maintain a healthy relationship. She eventually resigned to being alone and ceased pursuing romantic relationships after believing she had accomplished what she needed by having a daughter. Kendall said that only recently have her connections with other women hand cyclists with disabilities and their long-term partners shown her that it is possible to maintain positive, healthy, sustaining romantic relationships as a woman with a disability.

Kendall genuinely enjoys being a mother, although she has faced many people who did not believe it was possible for her to be a mother or to carry a pregnancy like a nondisabled woman can.

> When I was pregnant, the prenatal visits, the doctor I was seeing there was convinced I was gonna need a cesarean section without real evidence. I ended up going to a different hospital where they had a quote-unquote high-risk specialist. She said to me, 'Kendall, you can give natural childbirth just as easily as any able-bodied woman. Don't even worry about it.' And she was right. You know, I just popped this kid out.

She believes that having a disability has not limited her ability to be a mother at all. Instead, it has simply shaped the experiences they have shared together as mother and daughter. Kendall shared how she overcame her body image issues and how she worried about how others would perceive her when she would regularly take her daughter swimming at the public pool, “It was hard to feel so, like, I have these tiny, skinny little stick legs, and I look weird.” She chose to wear a bathing suit so she could be in the water with her daughter and “be the mom I wanted to be.”

Kendall had difficulty identifying with disability early on after SCI. Due to her attachment to her nondisabled body, she distanced herself from the disability community: “I didn’t really identify with it yet, and even though I was in a wheelchair and I was disabled, I felt still very much like an able-bodied person in a wheelchair.” Over time, she explained, she became occupied with managing the daily challenges of living with a disability, which became her new normal. As she has become more involved in adaptive sport, she sees herself more as a person with a disability. In fact, she came to recognize the ways that having a disability has been instrumental in shaping who she is and what she can do.

> Yes, I am a person like everyone else, but my being in a wheelchair affects me internally also, and in ways that can’t be seen from the outside. It’s directed the course of my life, the opportunities I’ve had or have not had, the struggles I’ve had, you know, there are so many ways that having a disability has shaped the kind of person that I am, that I wouldn’t be without the disability.

She also recognizes how others perceive her “as an inspiration and put way up on a pedestal, a hero, a fighter, a, you know, inspiration, and then on the other hand, a, you know, a

burden. A lesser than. Umm, not up to par." But she stated that, regardless of how having a disability has shaped who she is, what she can do, and how she is perceived, one thing that has not changed is that she is still "100%" a woman; "It's just the outward appearance" that is affected.

6.4.1.3. Synthesis. Kendall and Angela's narratives demonstrate the stagnating influence of attachment to a nondisabled past on narrative progression. This made it difficult for the participants to find meaning in their lives, satisfaction in their pursuits, and acceptance of having a disability. Similarly, both women expressed a disconnection with disability after SCI, which made it difficult for them to embrace the present and future with disability.

6.4.2. Narrative Two: Push for Recovery

Two participants, Chelsea and Eva, belonged to the narrative type *Push for Recovery*. This narrative is characterized by a focus on restoring the nondisabled body through continued rehabilitation and recovery efforts.

6.4.2.1. Chelsea. Chelsea is a White woman living in Minnesota who was 19 years old at the time of the interview. She was 17 years old, an active athlete involved in volleyball, basketball, and golf, when she acquired an L1 incomplete SCI in a motor vehicle accident in high school. Chelsea's narrative tone was characterized by optimism, positivity, gratitude, and resilience to "keep fighting" to enhance her function and strengths. In the early days after her SCI, Chelsea was disappointed that she could not live the way she wanted. She saw her SCI as a challenge to overcome, and she felt that she had no choice but to focus on improving her functional recovery after SCI. She said her motto was, "I can't do this right now, but I will eventually. I just need to keep working at it." This is an approach that she continued to

maintain and that was supported by her mother and professionals during her inpatient rehabilitation. However, this approach conflicted with the approach taken by the professionals in her outpatient rehabilitation, who focused more on increasing her independence rather than improving her functional recovery. Becoming fed up with this approach taken by rehabilitation professionals, Chelsea chose to continue to pursue her functional recovery goals by attending a gym that specialized in SCI and would help her improve her bodily function. She was rewarded for her efforts as she was able to strengthen her body and regain the ability to walk again with the assistance of mobility aids.

Although she has successfully regained much of her ambulatory function, Chelsea expressed the need to remain "hyper-aware" of her body and manage her neurogenic bladder with a regular catheterization schedule. This heightened awareness also influences how she navigates her environment: "I'm definitely like hyper-aware of when things aren't accessible." Chelsea observed that while she has been able to return to a life similar to what she had before her SCI, she is unable to participate in all the same activities as her friends.

When Chelsea returned to high school after SCI, she experienced discomfort at being seen in a wheelchair by her peers. She became determined not to use or be seen in her wheelchair again, instead relying on her other mobility aids. When she left home to attend college, she did so without her wheelchair as well. Chelsea's focus on functional recovery and the improvements she had seen also encouraged her to avoid using her wheelchair wherever possible. She expressed the belief that "Yes, I get tired walking, and like, there's things that are harder for me walking. But I'm like, since I'm able to, I should just, like, keep fighting and keep doing it over and over and over again until it eventually gets easier." Chelsea's belief that she

must continue to strive for greater functional strength due to her physical recovery has limited her relationship with disability. Consequently, she struggled to develop a comfortable connection with her wheelchair, rendering it inaccessible during situations where her ability to walk fell short. This avoidance of using a wheelchair also limited her adaptive sport opportunities. In addition, her guilt related to the progress made in regaining function has made her uncomfortable associating with disabled peers, hindering her ability to identify with disability: “I just identify myself as, like, a female, like going to college. Like, I don't really add that disability aspect in there.”

Although she does not view disability as part of her identity, she considers herself a strong person because of her disability and the challenges she has faced and continues to face. While having a disability has made her stronger, it has also presented unique challenges as a woman with a disability. She expressed,

> First off, it is really hard because it’s like I have to beat out all these men to get what I want, so that it adds like the factor. Like, I’m also behind the women because I have a disability, so I feel like a couple steps below, like, everyone because of, like, just being a woman and then having a disability.

To overcome the challenge of this unique experience of marginalization, Chelsea explained that she has to “work really hard” to achieve her goals. Despite the “double whammy” of being perceived and treated as inferior to both men and nondisabled women, Chelsea believes that having a disability “doesn't really, like, change who I am”; she still views herself as a woman regardless of having a disabled body.

Getting involved in adaptive swimming was a significant turning point in Chelsea's story. She found satisfaction in participating in adaptive sport and now considers herself a "swimmer." Because of this, along with the training and dedication she has shown to "figure it out and keep doing it," she continues to identify as an athlete. Engaging in adaptive sport helped transform her perception of disability and her relationship with her disabled body. Chelsea expressed gratitude for the opportunities she had as a member of her adaptive swimming team and for her connections with other women with disabilities with whom she has exercised. Interacting with other women who have disabilities, learning about their accomplishments, and experiencing their attitudes demonstrated to her that she can still achieve her dreams with a disability. These experiences also helped her come to terms with her body, acknowledge her limitations, and appreciate her strengths. Her experiences have helped her recognize that people with disabilities are just like everyone else, although they may have to do things a bit differently. She observed that individuals with disabilities are hardworking and believes that they tend to be more grateful and joyful for what they have.

6.4.2.2. Eva. Eva is a White woman living in California who was 48 years old at the time of the interview. She was 46 years old, an avid marathon runner and teacher, when she acquired a T9 incomplete SCI during surgery. Eva's narrative tone was raw and emotional, characterized by determination and hope for the future, as well as frustration with her body, her inability to run and be a runner again, and others' inability to accept her for who she is. Initially, Eva believed that, through persistent hard work, she would continue to see improvement in her condition: "I knew even with this initially, like the more I worked, the more I put into it, the more I was going to get out of it." Assuming this belief, developed from a sport

work ethic, Eva focused on walking again and regaining as much function as possible. Her rehabilitation experience, combined with the encouragement of many people in her life, heavily influenced this focus. Eva was rewarded for her efforts as she strengthened her body and regained the ability to walk again with the aid of a crutch. Over time, though, the reality of her impairment and the limits of her recovery became apparent. She expressed her impatience with herself but acknowledged that her life moves at a slower pace, requiring her to be more patient in completing tasks.

Eva reflected on her life before her SCI and missed the person she used to be. She felt frustrated by her body's stagnation in recovery, perceiving it as "broken." Even though she was able to walk with a mobility aid as someone with an incomplete SCI, she still viewed her body as impaired and visibly disabled to others. She expressed that her disability has impacted her self-esteem and self-image, influencing how she perceives her beauty, making it challenging for her to conform to societal standards of ideal femininity. As a result, she feels that her womanhood has become invisible.

> Before all of this, like, I was used to getting attention for being fit, attractive, healthy, vibrant, all of that. And now, you know, I'm the woman with the cane or the woman in the chair… I can't wear high heels anymore, and even in my nicest clothes, they don't fit the same. And even though I can walk, you know, I've got that pain as my sidekick… There is such a stigma attached to it, to even walking with a cane, that you know it's tough being a woman with a disability… I think that there is an expectation for women to be a certain way, and when you're not, you know you're less than.

Letting go of her halted recovery was a struggle, and accepting her disability proved to be a significant challenge. The limitations in her physical abilities prevented her from reclaiming her identity as the runner she once was. She had learned as a runner to always keep pushing for more, and this runner's ethic guided her still. As much as she did not know when to accept where she was, the attitudes of those people around her, who kept praying for her recovery and expecting her to become better, did not allow her to accept her disabled body. As a result, she felt caught between her sports instincts and what the people around her were telling her.

> Well, that's kind of why I don't want to go to Bible study, because you could keep praying I'm going to get better, but I'm not getting. I mean, and it becomes almost like a point of frustration because I just want people to be OK with, OK, this is just the way you are now. Because then I can be OK with it too, you know? And I don't know how long that takes for people to get to that, but it's been two years, two and a half years, and people are still praying for me.

In social situations, Eva felt the need to prove her capabilities. She believed that people focused solely on her disability when interacting with her. "I don't want to be seen as anything different than anybody else," she expressed, emphasizing her desire for acceptance. This internal pressure compounded her frustration over her loss of independence, "I can't do the same things, and I can't just hop in the car and go… If I, you know, want to do something, I need them to come to me and pick me up and take me somewhere." Eva's frustration led to conflicts with others who offered to help; she did not want to burden them. As a result of these internal and external pressures, she began to isolate herself at home, where she felt free from the worry of being perceived as different or less than what others expected.

Eva was able to return to teaching after SCI in an online capacity with accommodations. She explained that due to her impairment and the associated fatigue she experiences, online teaching was her only option, as she needed frequent breaks throughout the day. She feared that, because she had not communicated the full extent of her need for rest, she might lose her job if she were required to return to in-person work. Consequently, she lived in fear of the day when she would no longer be able to hide the extent of her disability and might not receive the accommodations she needed.

For Eva, being an athlete, specifically a runner, was her whole world. It encompassed her friendships, family life, and work roles. She felt a profound sadness over her inability to run and had not fully come to terms with the possibility that she might never run again. Eva clings to her athletic identity, yet she grapples with feelings of being an imposter since she can no longer participate as she once did. She has considered adaptive sport opportunities and has made connections within the disability community, but she has felt stymied by her lack of independence, local connections, and access to adaptive sport equipment.

> I don’t have the ability to get out and do stuff, right? I don’t have the ability to find, I mean, like, I don’t know anybody around here who does any adaptive sports… I’ve applied for grants to try and like get equipment like, can I get a racing cycle or a hand cycle? And, like, I get turned down for every one of them.

While she was frustrated with her lack of options, she continued to maintain hope that future adaptive sport participation was possible, and by developing her connections with others with disabilities, she could resolve her issues with sport and gain acceptance of her disability.

6.4.2.3. Synthesis. The women in this narrative type focused on restoring their nondisabled bodies through continued rehabilitation and efforts at recovery. They believed that, through hard work, they would regain their strength and make a functional recovery. Their narratives follow a similar progression as they work towards their goal of full recovery with each functional improvement. As their narratives progressed, Chelsea and Eva saw their efforts rewarded as they regained their strength in several areas and became capable of ambulating with a walking aid (e.g., crutch, cane). Their focus on functional improvement influenced their narratives, which became stagnant as their focus on restoration prevented them from moving forward in their relationship with disability.

6.4.3. Narrative Three: Embracing Life Without Embracing Disability

Two participants, Julia and Laura, belonged to a narrative type *Embracing Life Without Embracing Disability*, which refers to narratives characterized by achievements in adapting to disability and regaining independence, excellence in adaptive sports, and involvement in the disability community, but an inability to fully embrace disability.

6.4.3.1. Julia. Julia is a Native Hawaiian woman living in Nevada who was 27 years old at the time of the interview. Julia was 24 years old, an active athlete involved in two main sports (i.e., baseball and softball), when she acquired a T6 complete SCI in a snowboarding accident. Julia's narrative tone was characterized by determination, optimism, and positivity, accompanied by a willingness to embrace her new reality, which seemed insincere when discussing disability. After her SCI, she was adamant that she would not allow disability to hinder her from returning to her previous life. Julia was determined to regain her independence and worked diligently to enhance her capabilities during rehabilitation. When she returned

home, she felt the need to learn how to take care of her daily needs independently so she would not burden her parents or depend on anyone else because of her disability.

> My mom was going to go back to work but took an extra two months off because I kept having accidents in the bed when I got home. So, I was like, 'Oh my gosh, I have to figure out what is a way I can just set these little goals to make sure my mom doesn't have to come in every night or my dad, like, and help me because I felt so bad.'

Gradually, she worked hard to be able to complete one task after another without assistance. Julia explained the process of regaining her independence:

> I made a goal, like my mom didn't have to rotate me in bed, and I would work on that, and I've stuck to that, so that I got independent with that; she didn't have to go check on me. And then it was cathing. I had to cath in the middle of the night. I still couldn't get my legs right and my body right to cath, so I tried to work on that slowly, and then yeah, getting up in the morning, I had my clothes next to my bed, and I learned how to put on my socks and my pants and try to get dressed from bed because I didn't know how to do it in my chair yet. So little things like that, and then getting up, going to the bathroom and starting my bowel program, and doing that on my own, I still couldn't bend over and get my hands in the right position. So, I had to work on cathing and doing that, but my mom still assisted me. So, like everything that involved doing all those things again at home, I little by little. I just told myself it's going to take time, and I'll get it. I just have to stick to it. So eventually, like my mom didn't have to come check on me, and I was rotating, and then I cathed in bed. I got out. I went did my bowel program by

> myself. I finally cathed by myself. I got dressed by myself. I don't have to lay my clothes out anymore. I can get dressed in my wheelchair. I can just pull it out from the closet.

Julia successfully regained her ability to manage her daily needs, including transferring, skin care, and maintaining her neurogenic bowel and bladder, thereby enhancing her independence in everyday life. However, she explained that her adaptation process is ongoing as she continues to learn and adjust to gain more independence. For example, she has been learning from other women how to find the right position for catheterization with her female anatomy, and she has received assistance with modifying her clothing so she does not have to completely remove her pants when using the restroom. With unwavering determination, Julia also regained her ability to drive and live independently. She consistently challenged herself to meet her independence goals and continues to push herself to demonstrate that she is more capable than others might believe. Julia's strong desire to regain her independence in order to avoid burdening others and to prove her abilities indicated her dissatisfaction with appearing disabled or depending on others because of her disability.

Julia acknowledged having a disability but expressed a strong reluctance to identify with it. She rejected the term due to the limitations it implies. Julia explained that she finds it hard to see disability positively because her perception of disability is incongruent with that which she values most: athleticism, self-sufficiency, and independence. Consequently, she struggles to see herself that way. She shared her frustration about planning travel, where she has to filter her options based on accessibility, only to find her choices severely limited by the availability of accessible lodging.

> Even when you fill out a freaking questionnaire on a hotel or room or Airbnb, and you put in, like, has to be accessible, it literally closes down everything, and it's like no, but it has one little half-inch or maybe less step that makes it not accessible. But, like, I think the world just needs more education behind that. So maybe I'm just, like, explaining it on that terms, like, because when I say I have this, then it kind of eliminates all these other options for me. But I know I can do that stuff, so I, like, say, I don't have a disability because I'm super independent, if that makes sense.

Just as Julia disliked being defined by her disability, she also expressed gratitude when others did not “see the wheelchair”; rather, they only saw her, particularly at the start of new relationships. Unfortunately, as her relationships progressed and the reality of her disability asserted itself, difficulties arose (e.g., her partners' lack of acceptance of helping her care for her needs). These difficulties reaffirmed her negative association with her wheelchair and led to diminished self-confidence. Regardless of how others perceive her, Julia does not believe that having a disability changes the fact that she remains a woman, “It just makes me the person who I am and happy and wanting to be resilient and competitive and positive.”

In rehabilitation, Julia developed connections with others with SCI that she maintained once she returned home. Her connections with others with SCI, particularly women, helped introduce her to adaptive sports. Julia had struggled with the loss of nondisabled sport and her sport career aspirations after SCI, but her introduction to adaptive sports inspired and reassured her that she could continue pursuing her athletic passions. She still identifies as an athlete, attributing this to her heavy involvement in adaptive sports, where she trains diligently every day. She has also found renewed purpose and community through activities like sled

hockey, skiing, and CrossFit. Julia has set new athletic goals, including competing in the Paralympics, stating, “I want to be able to perform at the highest level and compete.” Julia recognized that her continued participation in sports and pursuit of athletic goals is vital to her happiness, so she found a job that supports both her career and athletic ambitions. Due to the mentoring she received from adaptive sport athletes, Julia embraced the role of an advocate for women athletes in wheelchairs, promoting accessibility and inclusion. She aims to serve as a positive representation of what women in wheelchairs can accomplish. Through her experiences, she has come to understand that people with disabilities are not only athletes but also have families. They are positive individuals who continually strive to overcome challenges and find solutions.

Julia believed that she was still figuring out how to live with SCI and navigate relationships, but she asserted that she was very happy with her life. She recognized the positives from her experience, expressing gratitude for the relationships she has gained and the opportunities she has to compete in adaptive sport.

6.4.3.2. Laura. Laura is a White woman living in Texas who was 63 years old at the time of the interview. Laura was 19 years old, an athlete involved in two main sports (i.e., basketball and skiing), when she acquired a T7 complete SCI while skiing during her sophomore year of college. Laura’s narrative tone balanced positivity with an honest acknowledgment of her struggles. Following her SCI, she resolved to “make the best of it” while maintaining hope and working towards the possibility of walking again. Her family’s faith in her recovery was something she recognized as “false hope.” Although she eventually came to understand that she would not walk again, she believed that this “false hope" from her family helped her cope

with her injury. After undergoing intensive rehabilitation and returning home, Laura was determined to live independently. However, she faced challenges in a world before the passing of the Americans with Disabilities Act of 1990, which meant her access to the community was limited. As she said, “I lived ten years with a disability, not being able in public, knowing that odds were there wasn't going to be a bathroom I could use.” Initially, due to her limited functional strength and discomfort with her capabilities, she restricted herself to only doing things she thought were essential tasks. However, as she became accustomed to her capabilities and gained more independence, she began to navigate her community with greater ease and embraced new challenges, stating she would “try anything.”

Laura took pride in having lived independently without caregiver support since returning home, as she wanted to avoid burdening others or relying on them for activities of daily living. Despite her confidence in navigating her community independently, Laura expressed frustration about having a disabled body that sometimes felt like it was not working with her:

> I'll tell people, you know, like, I'm not gonna be there tonight cause my body's not cooperating. It's like it's a separate entity. I even name my legs Fred and George because they might as well belong to somebody else.

Laura expressed her frustration not only with her uncooperative body but also with the significant time and effort required to complete daily activities, “I can't just get in bed like a normal person. It takes me a while, and I can't just get up and get on with my day like a normal person. There's all the stuff I have to do.” Tasks such as getting ready for bed, transferring, catheterizing, and following her morning routine—including her bowel program—have become burdensome for her, especially as she has gotten older.

Laura was mortified by her loss of control over bodily functions, particularly concerning her neurogenic bowel and bladder. She found it challenging to trust nondisabled individuals with this aspect of her needs. Along with these bodily insecurities, she also lost confidence in herself and her self-image, feeling inferior to nondisabled women, especially in sexual relationships, and believing that men viewed her as less of a woman. Consequently, lacking knowledge about what was possible for people with SCI, Laura believed she was no longer desirable, assuming she would not marry or have children due to her being in a wheelchair: "Who's gonna wanna marry me? Who, you know, much less have children. And how would that work anyway?" She experienced difficulties with dating as she pushed people away due to her insecurities. Laura discussed the lengths she went to hide her impairment-related needs from those she dated, fearing they would reject her.

> And then there was one guy that I dated. He was older. I was still in college. He owned a couple of nursing homes, and I was just really comfortable with him in a lot of ways, but I never really revealed to him. I tried to keep, like, he took me down to San Antonio for New Years, and I tried to hide, you know, the catheters and, you know, hide them in the trash can so he wouldn't know I was using, you know, just that whole thing just because it was embarrassing and, you know, and I didn't. I swear I don't think I drank anything that entire three days so I wouldn't pee on myself because I didn't want to have to wear a diaper. So, seriously, I don't think I drank anything for three days or ate anything.

It was not until she met her future husband, who had extensive professional and personal experience with people with SCI, that she felt comfortable revealing her needs.

However, once she separated from her husband many years later, the same insecurities about her body returned.

Laura and her husband are parents of two children. She shared the challenges she faced as a disabled woman during pregnancy. People were particularly surprised by her pregnancy announcement, especially her employer. She felt that her boss had been preparing her for a position with the assumption that she would not have "conflicts with family" that other women have: "That wasn't gonna be an issue with me because I would never have a family, right? Because I was in a wheelchair." Despite the looks and comments she received, Laura emphasized that she "reveled in it a little bit that, you know, hey, yeah, I'm disabled, and I can still have a baby."

As a mother, she took pride in her ability to independently care for and raise her children as their primary caregiver. Through various adaptations, such as modifying the crib, mattress, and carriers, as well as by teaching one child to help care for the other, she believed she had achieved all she wanted as a mother. Laura shared some challenges she has faced as a mother and caregiver with a disability due to others' perceptions of women with disability. She recalled the questioning she received when she called the pediatrician after accidentally dropping her daughter; they asked about potential child abuse, questioning her ability to care for her child. Now a grandmother, she expressed frustration at her own daughter's reluctance to let her take her granddaughter to the pool, indicating a lack of trust in her ability to care for her responsibly.

After her SCI, Laura struggled to identify as a person with a disability. She was reluctant to be viewed as disabled, as she associated that label with being defective, limitations, and

reliance on others. Laura believed that having a disability meant others would view and treat her differently from those who were nondisabled. Laura's reluctance to embrace her disability had a significant impact on her interactions with the disability community after her SCI. For instance, when she returned to college and resumed her involvement in academic service and leadership roles, she intentionally distanced herself from disability student organizations on campus and chose not to participate in a wheelchair beauty pageant, "I didn't want to be identified as, you know, Miss Wheelchair America, just, like, that would be embarrassing." She had avoided associating with that group of people because she did not view herself as "handicapped" like they were. However, despite her efforts to distance herself from disability, Laura faced the reality of disability prejudice and stereotyping when she tried to get a job after college graduation.

> I'll never forget, remember, this was before ADA, what the JCPenney recruiter said to me. She said, 'Your resume is so impressive, but I don't know how our customers would relate to you.' Yeah. That she actually said that. And yes, I did go home and cry after that, but the only job I was offered with this incredible, impressive resume and references from everybody, from the Dean of the School of Business who just loved me, to [Billionaire Entrepreneur], to Dean of Student life, and the only job offer I had was selling light bulbs for a disabled organization.

After her SCI, Laura believed she would never participate in sports again because she was in a wheelchair and was unaware of the opportunities available for individuals with disabilities. However, once she was introduced to adaptive sports, she relished the fun and competition that she valued from nondisabled sports. She emphasized her commitment to

training year-round to become a Paralympic athlete. Laura explained that being successful in adaptive sport, particularly at such a high level, and training alongside nondisabled athletes was esteem-building and brought her satisfaction. Through her involvement in adaptive sport, Laura met her husband, competed on an international level, and gained access to numerous opportunities that she believed would have been unavailable if she had never been injured. Her adaptive sport experience allowed her to preserve her athletic identity and connected her to the disability community, helping her overcome her initial hesitance about associating with others with disabilities. Subsequently, she took on service and leadership roles in various disability and adaptive sport committees and organizations, advocating for others.

As Laura aged and developed chronic injuries from a life with SCI and adaptive sport participation, she gradually withdrew from athletics; her withdrawal from participation in the disability community followed. Living independently became increasingly difficult for her. She has needed to carefully choose activities that align with her capabilities, resulting in the loss of many pursuits she once relished. Her growing dependence on others has been a challenge for her, but she has learned to embrace the necessity of accepting help to alleviate her physical burdens. Additionally, her comfort and attitude regarding her catheterization needs have improved, allowing her to be more candid about the challenges she encounters. Laura has accepted her disability as part of her new normal. With her daily routines occupying her focus, the thought of walking again has faded from her mind. While she acknowledges her disability and states that she has become more comfortable with it, she still prefers not to be defined by it. She identifies as a person with a disability because she does not want others to perceive the disability first. In fact, she appreciates it when others do not “see the wheelchair.” She

expressed, “I don't wanna be viewed as a disability. I wanna be viewed as a person. Look at what I can do, not what I can't do.”

6.4.3.3. Synthesis. The women in this narrative type embraced life with a disability, accepting their circumstances and participating in and advocating for adaptive sports and the disability community. However, they felt uncomfortable with the term "disability" due to its negative connotations. The women’s narratives followed a progressive plot as they sought to “make the best of it” (Laura) and regain their independence. Expressing a desire not to be a burden or depend on others for daily activities, they gradually adapted to their abilities and developed the strength to perform everyday tasks on their own. As their stories continued to progress, both women connected with individuals in the disability community who introduced them to adaptive sport. Julia and Laura reclaimed their passion for sport and forged relationships within this community. Their commitment to adaptive sport deepened as they took on advocacy roles, actively serving the community. Although their experiences in adaptive sport helped them accept life with a disability as their new normal, their narratives stagnated, and they struggled to fully embrace their disabilities.

6.4.4. Narrative Four: Transformation Through Shared Experience

Three participants, Gillian, Iris, and Miranda, belonged to a narrative type *Transformation Through Shared Experience*. This narrative type refers to narratives characterized by the transformative nature of shared experiences and connections with mentors and members of the disability community, particularly those who share an identity.

6.4.4.1. Gillian. Gillian is a White woman living in Washington, D.C., who was 28 years old at the time of the interview. She was 24 years old, an active athlete involved in lacrosse,

when she acquired a sudden onset of transverse myelitis, resulting in a C6 incomplete SCI. Gillian's narrative tone was characterized by resilience, determination, gratitude, and a sense of growing acceptance. Gillian pushed herself through intensive rehabilitation, hoping and expecting to achieve a full recovery. While she succeeded in regaining function that allowed her to be ambulatory using mobility aids (i.e., walker, canes, braces, and crutches), over time, she met the reality of her permanent impairment.

Gillian became frustrated, and it was hard for her to accept her injury. She did not want the life she was living, often expressing her frustration with her body. She remarked, "I was really pissed off about all I could see was the long list of things I couldn't do." Occasionally, she still feels angry about her body and its limitations. However, over time, she has come to accept that having a disability simply means her body is different. She understands that there are certain things she will never be able to do as easily as others. In particular, she recognizes that managing her bowel and bladder care needs is more challenging for her than it would be for a man due to her female anatomy. Despite this, she remains grateful for what her body can do. Gillian has learned to take care of her body, taking advice from one of her physical therapists who said, "Your body's like a high-maintenance car; you can't just trash it." As a result, she feels that she needs to think about her body much more and plan accordingly. This planning extends to how she navigates the environment,

> I have to think about, like, OK, you know, like, is the route I'm planning to get there as accessible is, like, the building accessible? Like, yeah. Like, where are the curb cuts? Where are the elevators? Like, how much time is it going to take me to do XYZ?

Gillian expressed that her heightened awareness of her disabled body has impacted her social interactions, particularly when meeting new people or going on dates. She shared that she often feels the impulse to hide her disability, questioning, "How long can I make them think I'm, like, quote-unquote, normal before I have to spill the beans?" She does not want to be perceived as disabled, believing that the public often views individuals with disabilities as “sad and pitiful.” Gillian shared that she tries to downplay her disability around nondisabled people, particularly her family.

> When I'm with my family or other able-bodied people, it's almost like I feel like I try to tone down the disability a little bit. It's like I'll use my crutches a lot more, or like, I'll try to sit down a lot more, like, I don't know, especially when I'm with my little cousins and stuff. It's like, I don't want them to grow up and see me as, just like, oh, Gillian's like the disabled one.

Gillian wants people to get to know her as a person first. During her interview for her current job, she was thankful that it was conducted online and that the position allowed for remote work. This setup enabled her to meet her boss and coworkers without revealing her disability. As she explained, "They got to know me based on what I could do, you know, and then not, like, oh, that's ‘the girl in the wheelchair’ or 'the girl with crutches.'" After nine months in the role, she received a promotion and wondered if that would have occurred had they been aware of her disability from the start.

As a woman with a disability, Gillian feels she endures a “double whammy" of discrimination. She explained, “It's like you get discriminated against first because you're disabled and then because you're a woman.” She added, “It's almost like I'm invisible… I guess

some people don't think you're capable of, like, having sex or having a relationship or getting married or whatever." Even during her rehabilitation, she claimed that none of the medical professionals she encountered provided resources or prepared her for the possibility of having sex or becoming pregnant with a disability. Consequently, she expressed that for a period of time, "It was sort of like my sexuality got, like, taken away or, like, took a backseat for a little bit." Despite how others perceive her, Gillian asserted that she still sees herself as a woman. Gillian explained that it took her a while, but she has become comfortable with thinking about and reclaiming her sexuality and dating again.

Gillian told of how, after SCI, she avoided others with disabilities and similar injuries to hers. She did not want to be like them. She was still attached to seeing herself as a nondisabled person. At the same time, she struggled, frustrated at not knowing what she could do with a disability. Things began to change the more Gillian saw people like her living their lives:

> It's like you go on, like Instagram, and you see all these people, like doing adaptive sports or in wheelchairs or whatever. And you're like, OK, like, no, I can have a normal life in a wheelchair, like they even make it look like, kind of cool or, like, kind of sexy or whatever.

Seeing other people with disabilities and meeting other people with disabilities who were living their lives assured her that a normal life with a disability was possible and validated her own experiences:

> So, like, seeing other people who could, like, also be successful with spinal cord injuries, I think, was a big shift in, like, my attitude toward it because it was sort of like, OK, if these other people can do it, then I can do it, too, you know.

Gillian's attitude toward disability began to change, becoming more positive, particularly as she became more involved in adaptive sports. Gillian enjoyed participating in adaptive sports such as wheelchair tennis, skiing, rock climbing, and cycling, relishing the thrill of "being able to go fast and get that adrenaline rush." These experiences allowed Gillian to maintain her identity as an athlete, as she recognized that participating in adaptive sports has become an integral part of who she is. However, she felt that the strength of this identity had diminished as she missed the freedom of movement she experienced with her body while playing lacrosse before her SCI. Additionally, she disliked the competition level in adaptive sports and the way that nondisabled people often perceive and treat these activities as less legitimate forms of athletics. When she was introduced to adaptive sport and had the opportunity to meet, ask questions, and share experiences with other adaptive sport athletes, she said that it allowed her to be open and comfortable discussing disability and being disabled. Gillian's interactions with others through adaptive sport allowed her to feel connected to the disability community, helping her to embrace her identity as a disabled person. She now views disability as a part of who she is, believing that it signifies a unique adaptability. According to Gillian, being disabled means being part of a community that faces challenges different from the norm and taking pride in that experience.

6.4.4.2. Iris. Iris is a White woman living in Vermont who was 52 years old at the time of the interview. Iris was 46 years old, an avid runner and cyclist, when she acquired a T5 complete SCI when struck by a car while cycling. Iris's narrative tone was characterized by determination, positivity, and pride, but it also carried an undertone of frustration. Iris feared returning home and being dependent on her parents. She was determined to continue living

independently, so she relied on her sport-developed work ethic (i.e., the more you put in, the more you get out) to drive her through rehabilitation, motivated by any modicum of progress in functional improvement. After rehabilitation, Iris returned home with a focus on gradually regaining her independence. She aimed to get comfortable navigating her community, return to work, and adapt to her new reality of living with a disability. She began simply by venturing out to the grocery store. With each successful outing, her sense of accomplishment grew, boosting her confidence in her capabilities. She shared that she gradually learned “tricks" to manage her daily needs more easily. For example, she used small disposable catheters and modified her pants so she did not have to struggle to take them off every time she went to the bathroom, which was very challenging even in accessible bathrooms. Reflecting on her experiences, she stated, “I’m pretty proud of myself for what I can do, what I can do with a disabled body.” This was important to Iris, as she felt that her disabled body meant she was perceived as different. She expressed, “It’s just this glaring thing, you know, like, I’m disabled. I’m in a wheelchair. That’s very prominent in my mind as I’m doing anything in this world.” Iris also detailed the emotional challenges she faced after returning home:

> I remember the first time when I first got home; I’d had, like, meltdowns every couple hours where I’d just be, like, wailing like a baby, like, fuck! And then it went to a couple weeks. And then it was like, you know, a month would go by before I’d have a meltdown.

She needed to emotionally adjust while learning to manage the practical difficulties of her neurogenic bowel and bladder. Dealing with the physical realities of having a disability has

become a significant part of her daily life. “It takes so long to get ready in the morning; it takes me, like, two and a half to three hours to get up and out the door.”

Iris shared that her first experiences with other women with SCI occurred while she was still in rehabilitation. She explained how these experiences validated her emotions and helped her to adapt during a difficult time in her recovery. She emphasized that connecting with other women with spinal cord injuries is “the best, because then you can… talk about all your shared life experiences that are so unique, and, I don't know, you just connect on a new, different level.” While she was undergoing rehabilitation, she also feared facing who she was without sport and being a runner once she left. Based on her previous knowledge of disabled athletes and her desire to compete and participate in sports again, Iris was guided by a vision of being a disabled athlete. When she returned home from rehabilitation, she sought opportunities to participate in adaptive sports. She attended a women’s adaptive sport event, which she found to be “transformative.” This event allowed her to connect with other women athletes who have SCIs. By seeing and interacting with them, as well as hearing their experiences of living with disabilities, she became convinced that she could do what they were doing.

> So, I mean, I was the newest, most newly injured. Everyone else had been, like, three years, five years, fifteen years, and they had families and boyfriends and jobs. And they were doing sports. And to just see, like, I was like, OK, if they can do it, I can do it. So, it was incredibly motivating. And it was also just like so helpful to ask these questions, like, ‘How do you deal with nerve pain?’ And they’re like, ‘Don’t worry, it gets better. Like, eventually, it’s still kind of there, but it’s not as present and torturous.’ Everyone was, like, ‘Three years. It just takes three. You know, like, in three years you’ll be OK. Like, a

> lot of this stuff, you'll figure out the UTIs better, and you'll know your body better, and your body will settle down because it's like getting used to this.'

Iris delighted in the experience and expressed gratitude for the other women's shared experience, knowledge, and encouragement. She would take this information along with the connections she had made and rely on them beyond the event.

> It just was so helpful to have that. So I, even if three years felt like an eternity away, I knew that there would be a time, like, things would get better. And I saw them, and how independent they were, and how easily they moved around, and just watching them zip around in their wheelchairs. I was, like, oh, OK, cool. Like, that's, I can get there. I'll get there. So, I went home with this newfound confidence and motivation. And also, just, it was, I met some friends that are still, like, my besties to this day.

Iris returned to competitive sport participation via adaptive sport. She joined a women's competitive hand-cycling team and "got really tight with all those women" as they engaged in rigorous training and competed in races nationwide. As a result, she perceived that she was "still an athlete," but there were aspects of her athletic experience that were "just different." She complained about not being able to be as free, daring, and capable as she used to be, which was challenging.

Iris built close relationships with other women athletes with disabilities. These women were her role models and helped her develop a positive outlook and an understanding of what she could do with her disability (e.g., work and relationships). Iris's connections with disability mentors in rehabilitation inspired her to pay it forward. She decided that she wanted to combine the work, sport, and disability aspects of life to help support the adaptive sports

community. She has since become a leader of an adaptive sport foundation, which is a role that she is very proud of.

Iris identifies as disabled and a wheelchair user. She believes that being disabled means life can be challenging, stating, “You can’t do things the same way that other people do.” Despite this, she views people with disabilities as creative, patient, gritty, and positive. Over time, Iris has become more comfortable identifying with disability, yet her relationship with her body remains complicated. Although she takes pride in what she has accomplished with a disabled body, Iris shared that it is hard for her to accept how her body looks now, “I think it's hard from going from, like, and I was in really good shape. I looked pretty good. To go from, like, feeling super attractive to, like, OK, I'm in a wheelchair.” She expressed frustration with her body because of how it has become a constant presence as a dysfunctional entity.

> I’m obsessed with my stomach, and just, I mean, it always is hurting and bloated. And I’m always, like, touching it. And. I mean, I’m also in pain all the time. So, it’s like this. I don’t know. It’s like a negative. It drives me crazy, whereas it used to be a wonderful thing. It’s, like, constantly in pain and, uh, uncooperative.

Iris has faced new challenges with her body insecurities as she has begun a relationship with a nondisabled man. She described experiencing "waves of insecurity, feeling like, uh, just like, I’m insufficient,” as she learns more about how having a disability affects her sexually. Additionally, she expressed reluctance to disclose her bladder care needs to her partner. Iris tries to reassure herself by remembering that “he chose me,” but this relationship has introduced new challenges related to her disability that she has found difficult to accept.

6.4.4.3. Miranda. Miranda is a White woman living in Pennsylvania who was 33 years old at the time of the interview. She was 20 years old, an athlete involved in two main sports (i.e., soccer and snowboarding), when she acquired a C5/C6 incomplete SCI in a motor vehicle accident in college. Miranda's narrative tone was characterized by a pragmatic acceptance of her life with SCI, conveying positivity and optimism about the future. After her SCI, Miranda hoped for a swift recovery. During her rehabilitation, which included a second stay following bladder surgery, she focused on learning about SCI and her body, strengthening herself, and figuring out her capabilities while being careful not to overextend herself. While she was figuring out how to use her body again, she felt dissatisfied with her disabled body and the appearance of her "quad belly." She viewed her disability negatively, interpreting it as a sign of incapability. She shared how others demonstrated this through their actions,

> Yeah, so sometimes people, like, jump in and try to help you with something without asking or just start, like, pushing you out of nowhere. I'm, like, you don't even know where I'm going, like, I'm at work. What are you trying? I don't even know. So yeah, so from their minds, they're like, oh, this person's disabled, they definitely need help.

Miranda experienced difficulties during the first few years after SCI in part because, without nondisabled sport, she had lost a trusted coping resource when facing difficulties in her life. Miranda was unaware of adaptive sport, and her capability to participate in sport activities in her community was very limited by a lack of opportunity. Miranda was also initially avoidant and hesitant to engage with the disability community due to her own discomfort with her disabled body and unfamiliarity with the community.

About two years after her SCI, Miranda connected with a peer mentor after her second stay in rehabilitation. She developed a treasured friendship with her mentor, a woman with a SCI, who provided invaluable shared experience and knowledge that she “didn’t get to learn from anyone else because guys with spinal cord injuries are a lot more common.” Her mentor helped normalize disability and connected her with the disability community. This mentor relationship was more impactful than her other relationships with people with SCI; Miranda emphasized the value of “just having another woman that went through a lot of similar things as me.”

Miranda’s mentor introduced her to wheelchair rugby, which enabled her to maintain her athletic identity and helped normalize disability beyond the realm of sport. Miranda shared how, through adaptive sports, she has found many mental and physical benefits and has relished her opportunities to compete both nationally and internationally in wheelchair rugby. She emphasized her gratitude for the opportunities she has had to travel for adaptive sport: “That wouldn’t have happened if it weren’t for my injury.” Miranda also expressed her gratitude for the people she has connected with after her SCI, including the adaptive sport community and SCI organizations. Through the connections she formed within the wheelchair rugby community, she learned how to better navigate life with a disability.

Now, Miranda finds it easier to identify with disability, having been actively living with it and engaging with others who share similar experiences. Miranda stated that she considers herself disabled primarily due to her awareness of how others perceive her when they see her in a wheelchair. Additionally, she feels that the salience of her disability varies based on her environment, which is influenced by factors like accessibility and familiarity. Moreover, Miranda

does not perceive that having a disability has affected how she sees herself as a woman, “It's just, like, part of it because I don't see it as a bad thing; it's just a thing.”

Miranda has developed a supportive peer network of women with SCI who support her through shared knowledge and experience. These relationships, alongside various media portrayals of disability, have further normalized disability for her and demonstrated the possibilities available to her. She continues to maintain involvement in the disability community and wishes to pass on the support she has received to others in need.

6.4.4.4. Synthesis. The women in this narrative type highlighted the importance of shared experience and connections with mentors and other members of the disability community, particularly those who share identity (e.g., woman, athlete, disability), in transforming the lives of women with SCI. The women identified the turning points in their stories as the interactions they had with other individuals with disabilities, the sharing of knowledge and experiences, and seeing people with disabilities engaging in everyday activities in media and in person. They emphasized the value of peer mentors who were also women with disabilities, as they connected through their shared experiences. While they shared similar turning points in the development of their stories, the women detailed different paths to arrive at these turns. Various factors influenced when these turns occurred, including the timing of their exposure/interaction with other women with disabilities, avoidance of people with disabilities, and lack of adaptive sport awareness.

6.5. Discussion

The aim of this study was to use a narrative inquiry approach to explore the disability narratives of women athletes after SCI and to document the meanings they attribute to

experiences of psychosocial adaptation to acquired disability. More specifically, the study focused on capturing what meanings are attributed to *having a disability*, *being disabled*, and *living with disability*. Narrative analyses revealed four types of narratives: *Attachment to a Nondisabled Past*, *Push for Recovery*, *Embracing Life Without Embracing Disability*, and *Transformation Through Shared Experience*. What follows here is a discussion of what these narratives tell us about (a) being a woman athlete with a disability after SCI, and (b) what it means to have a disability, be disabled, and live with disability.

6.5.1. Woman Athlete After SCI

The women's narratives demonstrated that, in comparison to men, living with a disability is more complicated due to unique challenges related to female anatomy, particularly those that complicate access to the urethra. The narratives illustrated how the women had to navigate added challenges in their daily intermittent catheterization process. Compared to men, the women needed to undress more to gain access, faced greater uncertainty in having suitable facilities for catheterization away from home, and dealt with increased difficulties in performing the procedure with limited dexterity in their hands and arms. These constraints are consistent with previous research that highlights the distinct obstacles women with SCI encounter, particularly in catheterization (Nevedal et al., 2016). To remedy these obstacles, many women in this study shared that they underwent the suprapubic surgical procedure to ease the challenges in the management of their bladder care needs.

The women's narratives also highlighted how their SCI rehabilitation experiences were shaped by an apparent male-centric approach to care. The women perceived that the available resources (e.g., materials on sexuality with SCI) and care strategies (e.g., questioning emotional

expression and interpreting it as indicative of "mental instability") were predominantly designed for men, and in general, inadequate to support the women's unique needs. During their rehabilitation, little to no materials or medical professionals provided information and support on how to navigate the possibilities of issues such as pregnancy and motherhood post-SCI, leaving the women feeling ill-prepared. Thus far, limited research has found few gender differences in overall patient experience or rehabilitation outcomes (Bychkovska et al., 2024; New & Epi, 2007). It is known, however, that the minority status of women with SCI can mediate rehabilitation experiences in subtle ways to leave women feeling overlooked, inferior, or different (Samuel et al., 2007).

The stigma surrounding having a disability and the use of assistive technology, such as wheelchairs and canes, was perceived as preventing the women from meeting societal standards of femininity and beauty, and marking them as insufficient or inferior to other women. The narratives showed how the women felt that they had become "the woman with the cane" or "the woman in the wheelchair," making them feel invalidated as women. Such perceptions contributed to body image issues and frustrations with aspects of their bodies that could not be changed, resulting in feelings of being less attractive, less desirable, inadequate, and inferior compared to other women. These findings are unsurprising and consistent with existing literature that indicates both men and women with disabilities perceive themselves as unable to meet societal ideals of masculinity or femininity (Bucciere & Reel, 2009; Reel & Bucciere, 2010). Men and women with disabilities have been found to believe their ability to achieve these gender ideals will be questioned due to possessing "discrediting attributes" (Goffman, 1963), which label their bodies as defective or deviant (Reel & Bucciere, 2010). This

study's findings of the women's perceptions of the invalidation of their womanhood due to the intersection with disability stigma also align with existing literature suggesting women with disabilities are viewed as excluded from true womanhood and feminine beauty (Garland-Thomson, 2002). This feeling of being unable to achieve societal standards of femininity can lead to a diminished sense of self-worth and poor body image, as supported by previous research (Reel & Bucciere, 2010).

The stigma surrounding having a disability was also perceived as making the women invisible as sexual beings. They believed others doubted their ability to have sex, their capacity for sexual attraction, their potential for loving relationships, or whether they were capable of having children or being mothers. The narratives showed the challenges the women encountered in dating and maintaining romantic relationships, stemming from the internalization of disability stigma and associated body insecurities. These included trusting partners with knowing their impairment needs, feeling inadequate compared to nondisabled women, and reclaiming their sexuality. The women's narratives also showed the challenges they faced as mothers and caregivers, including others' assumptions that they were unfit to have children and questioning their ability to care for children, including employers, medical professionals, and family members. Such perceptions are consistent with cultural narratives that portray women with disabilities as lacking sexual agency, unfit for motherhood, and inadequate in traditional female roles, ultimately undermining their status as women (Fine & Asch, 1988; McDonald et al., 2007).

Despite having a disability affecting how they were viewed as women, the women in this study asserted that they continue to see themselves as women. They demonstrated a

strong belief that, while SCI may uniquely impact their bodies and disability stigma influences the perceptions and treatment they receive from others, having a disability does not negate their identity as women or their womanhood. This belief, along with their actions reflected in various narratives about healthcare and motherhood, demonstrates their ability to make independent decisions, even when those decisions differ from what others might believe is in their best interest. Furthermore, their independent decision-making illustrates the women's ability to control their lives in ways that counter prevailing disability narratives. Through the exercise of autonomous agency in their narratives, the women challenge disability stigma and create new avenues for their stories to unfold.

The women viewed themselves as athletes and had been invested in maintaining their athletic bodies prior to SCI. After SCI, their lives continued to be shaped by their athletic identity and their participation in fulfilling athletic pursuits. The women who told a "nonathlete" narrative (Perrier et al., 2014) discussed how their physical impairments prevented them from seeing themselves as athletes, as their bodies could no longer function the way they used to. These women shared their frustration that their SCI had interfered with an athletic body they were confident in and satisfied with. Their attachment to previous embodied identities as "runners" or "cyclists" negatively influenced their desire to explore adaptive sports opportunities. As a result, they struggled to find satisfying athletic outlets and reclaim their athletic identities.

The narratives also emphasized that a crucial factor in effectively countering the pervasive stigma surrounding disability and facilitating their continued participation in sport was seeing and actively engaging with other women with disabilities, particularly women

athletes with disabilities. The narratives showed how the sport participation, successful careers, and meaningful relationships of women athletes with disabilities served as powerful positive role models, demonstrating what is achievable despite societal limitations. These supportive relationships provided the women with the encouragement, confidence, and validation needed to adapt to their unique circumstances, ultimately normalizing disability and allowing them to embrace their bodies more fully.

The women who shared stories that aligned with a “the athlete as a future self” narrative (Perrier et al., 2014) discussed how their adaptive sport experiences were not the same as their nondisabled sport experiences and could not “measure up” to the commitment and competition they associated with nondisabled athletic experiences. These women struggled to identify as athletes because their adaptive sport experiences lacked valued elements such as freedom, spontaneity, and competitive levels that they associated with their nondisabled sport participation, thus hindering their satisfaction with the experience.

The women involved in adaptive sports, who discussed their current sport behaviors and future sport goals, shared stories that aligned with the narrative of “the present self as athlete” (Perrier et al., 2014). The women who told this narrative demonstrated how they had (a) mitigated the loss of their pre-injury athletic identity, (b) regained aspects of their sport experience that brought satisfaction, and (c) discovered renewed athletic purpose and joy. The narratives showed that sport had become much more important to these women athletes after SCI because of what it offers them in terms of maintaining their physical health and social connections. The narratives also showed that their success in adaptive sport was esteem-

building, and it had become an integral part of their identity in much the same way that participation in nondisabled sport had.

In summary, the narratives identified in this study suggest that being a woman athlete with a disability after SCI means (a) facing unique challenges due to female anatomy, (b) experiencing SCI rehabilitation shaped by a male-centric approach to care, (c) disability stigma affecting perceptions of femininity, womanhood, and sexuality, and yet, (d) continuing to see oneself as a woman. The narratives also suggest that women's athletic identity and disability stigma influence their athletic lives after SCI, and a key factor in countering this stigma and facilitating continued participation in sport was seeing and actively engaging with other women athletes with disabilities.

6.5.2. Having a Disability

In this study, *having a disability* was conceptualized as the meaning assigned to possessing an impaired body as one navigates the world. Based on the narratives, the women in this study extend the above by characterizing *having a disability* as (a) an embodiment of disability stigma associated with the physical body and (b) social-relational in nature.

For the women, *having a disability* meant the embodiment of disability stigma associated with the physical body and the visible aspects of physical disability. The disability stigma is heavily focused on the limitations of the physical body and what it cannot do. This aligns with existing conceptualizations of disability, as it frames disability as a problem, a deficiency, or a divergence from the standard that requires correction (e.g., Oliver, 1990; Thomas, 1999; WHO, 2001). The embodiment of disability stigma in *having a disability* showed through the narratives by women discussing how they felt they were viewed by others as a

burden, lesser than, pitiful, or dependent. Equally, the narratives showed how the women exhibited self-stigma as they had internalized the disability stigma by using terms like “broken,” “defective,” and “flawed” to express their beliefs that the disabled body was lacking. This disability stigma complicated the women’s relationships with their bodies, influencing their emotions and actions. The women discussed feeling compelled to distance themselves from the term “disability” and from disabled individuals, especially following their SCI. Some women attempted to hide or minimize their disabilities, even going without their wheelchair entirely, to avoid confirming the disability stigma. This disability stigma also made it increasingly challenging for the women to love their bodies as they had before SCI, primarily due to how the disabled body looks, feels, and functions. The narratives showed for some of the women, the lack of love and the disconnection from their bodies was particularly evident. Iris, Kendall, and Laura, in particular, described how they perceived their bodies as separate entities from themselves due to their bodies acting in ways that no longer aligned with their personal intentions or desires. Additionally, the disability stigma led to social isolation, as some women avoided situations where they feared they would be judged or treated differently because of their disability.

In line with the social-relational model of disability (SRM; Thomas, 1999, 2007), the women’s narratives also highlighted *having a disability* as being social-relational in nature, indicating that disability is something imposed on top of the physical reality of impairment through the influence of social and relational factors. Consistent with the SRM, the women shared how their physical impairment had immediate and direct effects on their feelings and capabilities due to constraints such as chronic pain, bowel and bladder incontinence, and

pressure sores. They also detailed how their relationships with the social environment led to social restrictions on their activities, which in turn undermined their psychosocial well-being. The women's narratives supported four specific social contexts identified by the SRM, where disabled individuals experience social oppression as a consequence of social restrictions stemming from (a) disabling social barriers (e.g., inaccessible environment and employment discrimination), (b) negative experiences with cultural constructions of disability (e.g., interactions with negative societal attitudes and stigma), (c) negative experiences with structural disablism (e.g., frustration at inaccessible buildings), and (d) self-imposed restrictions based on internalized ableism (e.g., distancing from disability community, self-isolation).

The disability narratives in this study support contemporary literature that considers *having a disability* to be a product of the interaction of individual, environmental, and social factors (Thomas, 1999; WHO, 2001). The women's perceptions of their physical bodies influenced how they viewed their social relations and environmental factors, and conversely, their views of social relations and environmental factors shaped their awareness, perceptions, and interpretation of their disabled bodies. This cyclical relationship found in the narratives supports existing research (Haslett et al., 2017) and aligns with the SRM (Thomas, 1999, 2007), highlighting the vital role of social structure and social agency in understanding what it means to *have a disability*. Based on the narratives, women in this study appeared to exercise social agency in an autonomous (as opposed to passive, as depicted in the SRM) manner. For example, some of the women discussed how they took personal responsibility for caring for their bodies in ways that challenge prevailing cultural narratives that portray people with

disabilities as passive agents who are, for the most part, reliant on others and subject to external pressures and authority.

In summary, the four narrative types identified in this study suggest that *having a disability* is (a) an embodiment of disability stigma associated with the physical body and (b) social-relational in nature. These align with contemporary literature that indicates disability is defined as a problem, deficiency, or limitation (e.g., Barnes, 1991; Leonardi et al., 2006; Thomas, 1999) and a product of the interaction with social structure and social agency (Thomas, 1999). The results extend the current literature by taking into account the autonomous agency that women athletes with disabilities demonstrate in their experiences of *having a disability*.

6.5.3. Being Disabled

In this study, *being disabled* was conceptualized as the meaning assigned to disability identity and the effect that it has on the relationships with self, others, and the surrounding environment. Based on the narratives, *being disabled* is characterized as (a) identifying with the disability stigma associated with *having a disability*, (b) malleable in nature, (c) constructed in relation to both disabled and nondisabled people, (d) typically perceived and discussed in a paradoxical manner, and (e) comprised of internal and external dimensions.

According to the women's narratives, *being disabled* meant identifying with the disability stigma that was associated with *having a disability*. As explained above, the disability stigma is centered on the limitations of the physical body, dependence on others, and inability to contribute meaningfully to the workforce. The narratives showed that the women internalized this disability stigma, leading some to believe that identifying with a disability was a

label that would limit their opportunities in life and at work. They felt they would be perceived and treated differently, which prevented them from fully embracing their disability as part of their identity. This aligns with existing research (Bogart et al., 2017) that recognizes stigma as a predictor of disability identification. The narratives showed that the women's reluctance to identify with disability or connect with others who have disabilities was particularly strong in the early years following SCI. The women insisted that they were "not one of those people" and focused on achieving recovery and rehabilitation goals to restore their bodies and former selves. The narratives illustrate the women's deliberate acts to downplay or hide their physical disabilities and distance themselves from the disability community. Some concealed their disabilities out of fear of discrimination in employment or social situations like dating. The apparent reluctance to openly disclose their disabilities further limited the women's ability to identify as disabled.

The narratives also suggest that *being disabled* is malleable in nature. The women's narratives captured the progression of their disability identity development and the barriers and facilitators that were essential to that development, which aligns with a considerable amount of the literature on *being disabled* that emphasizes the development of disability identity (Caldwell, 2011; Gibson, 2006; Gill, 1997; Forber-Pratt & Zape, 2017). This finding also supports existing research that shows identities are not fixed but have the capacity for change and/or movement (Schöpflin, 2001).

The women's narratives also demonstrated how *being disabled* was constructed in relation to both disabled and nondisabled people. The women who had formed strong relationships with others with disabilities, especially women athletes with disabilities, reported

feeling more at ease identifying as people with disabilities and engaging with the disability community. Contemporary literature supports this finding, emphasizing the influence interactions with others with disabilities have on integrating disability into the self-concept (Caldwell, 2011; Gagliano, 2021; Gibson, 2006; Gill, 1997; Forber-Pratt & Zape, 2017). The narratives also showed that those who participated in adaptive sports reported numerous benefits from having opportunities to connect with other women athletes with disabilities. This helped the women envision what was possible for women with disabilities, become more comfortable discussing disability, and normalize their experiences, ultimately allowing them to embrace an identity as an individual with a disability. This aligns with existing research (Groff & Kleiber, 2001; Groff et al., 2009) that indicates participation in adaptive sport and social interactions with others who have disabilities in this context fosters identity negotiation, encourages positive group identity development, and helps reshape perceptions of disability. The narratives also showed how relationships with nondisabled individuals often impeded the ability to express and develop disability identity. Many women felt compelled to downplay disability when around nondisabled people. Additionally, the attitudes and expectations of nondisabled individuals made it challenging for the women to accept *being disabled*, thus highlighting the significant influence of social relationships with nondisabled people on the development of disability identity. This insight extends current understandings of disability identity development, which typically focus on relationships with other disabled individuals and experiences of discrimination (Caldwell, 2011; Gibson, 2006; Gill, 1997; Forber-Pratt & Zape).

While the women's perceptions of *having a disability* and *being disabled* were associated with disability stigma, and the women acted to protect themselves from that

stigmatized identity, the narratives also revealed that the women typically perceived and discussed *being disabled* in a paradoxical manner. Across the narratives, the women characterized people with disabilities as positive, joyful, proud of their accomplishments, and grateful for what they have. Additionally, they highlighted traits such as industriousness, adaptability, creativity, patience, perseverance, grit, and strength, emphasizing that people with disabilities have the ability to overcome commonly shared challenges of *living with disability*. Furthermore, they recognized people with disabilities as athletes, parents, and members of a community. Several women emphasized that people with disabilities are just like everyone else; they simply have to do things differently. These perceptions challenge the disability stigma the women associate with *being disabled* by suggesting that being different does not mean they are less than others. Consistent with existing research on in-group favoritism (Hewstone, 1990), the narratives show that while the women were reluctant to identify with disability due to disability stigma, they were also inclined to highlight the positive traits and behaviors of a group they implicitly understood they belonged to.

The narratives also showed that the women who had come to identify as a person with a disability recognized disability as a part of who they are and that *being disabled* has impacted them “in ways that can’t be seen from the outside” (Kendall). This, along with the women’s perceptions of people with disabilities discussed above, supports the notion that disability identity has both internal and external dimensions. That is, *being disabled* is both personal and intrinsic to the individual and communal and shared (Caldwell, 2011; Dunn & Burcaw, 2013; Forber-Pratt & Zape, 2017; Gill, 1997; Putnam, 2005). The narratives in this study showed how

both internal factors (e.g., personal meaning, pride, acceptance, and resistance) and external factors (e.g., communal attachment and stigma) influenced self-identification.

In summary, the four narrative types identified in this study suggest that *being disabled* is characterized as (a) identifying with the disability stigma associated with *having a disability*, (b) malleable in nature, (c) constructed in relation to both disabled and nondisabled people, (d) typically perceived and discussed in a paradoxical manner, and (e) comprised of internal and external dimensions. This aligns with contemporary literature that suggests disability identity develops in relation to one's personal beliefs and perceptions of *having a disability* and their shared experiences with and cultural understandings of the disability community (Caldwell, 2011; Dunn & Burcaw, 2013; Forber-Pratt & Zape, 2017; Gibson, 2006; Gill, 1997; Putnam, 2005). The findings extend the current literature by taking into account the influence of relationships with nondisabled people in their development of *being disabled*.

6.5.4. Living with Disability

In this study, *living with disability* was conceptualized as the meaning assigned to the process of adaptation to disability and the factors affecting the process. Based on the narratives, *living with disability* is characterized as (a) a challenge to overcome, (b) having the potential for positive outcomes, (c) being a multidimensional process, and (d) being an ongoing journey. The key factors that affected the process included the relationships with both disabled and nondisabled individuals.

According to the narratives, *living with disability* was a challenge the women had to overcome while working towards recovering as much function as possible and returning to pre-injury lives. The narratives were characterized by a belief, particularly in the initial years

following SCI, that through concerted efforts at rehabilitation, they would make a full recovery. This is consistent with existing research on *living with disability* that often frames acquired disability as a problem or disruption in need of remedy and describes a successful outcome of the adaptation process as a return to normalcy – the status quo (Bishop, 2005; Devins & Shnek, 2000; Kendall & Buys, 1998; Livneh, 1986, 2001). The women's narratives often followed a restitution narrative, which, according to Frank (1995), is a dominant narrative in Western cultures that conveys hope for recovery after an illness or injury. Its basic storyline is: "Yesterday I was healthy, today I am sick, but tomorrow I will be healthy again" (Frank, 2013, p. 77). In the context of SCI, this storyline has been adapted by Smith and Sparkes (2005) to state, "Yesterday I was able-bodied, today I'm disabled, but tomorrow I'll be able-bodied again" (p. 1096). As shown through the narratives in this study, the women perceived *living with disability* as a temporary disruption, expecting a return to their pre-injury way of life, normal functioning, and/or their former selves after a successful recovery. Several women discussed the challenges they faced in moving beyond this narrative due to the various internal and external influences in their lives. They experienced pressure from an internal drive to continue striving for improvement as they rehabilitated their injuries as well as from the expectations of the nondisabled people around them.

The women's narratives also demonstrated that *living with disability* has the potential for positive progression and outcomes. Although many of the women's narratives followed a restitution storyline, they continued to evolve and shift over time. The women had lived for years after their SCIs and had to confront the reality of having a permanent impairment, which often led to adjustments in how they approached *living with disability*. Some of the narratives

in this study also reflected elements of a quest narrative (Frank, 1995), indicating a deliberate choice to confront SCI directly, accept the situation, and "make the best of it." The quest narrative was shown through the women's beliefs that there was something they had gained from the experience of *living with disability,* such as enabling them to "pay it forward" to others. This contradicts current literature, which typically characterizes *living with disability* solely as a problem or disruption that leads to negative perceptions and chronic sorrow that people with disabilities must overcome (Bishop, 2005; Devins & Shnek, 2000; Kendall & Buys, 1998; Livneh, 1986, 2001). The narratives in this study showed that *living with disability* can create unique opportunities in adaptive sport and foster valuable connections within the disability community – both of which may not have been possible without a disability. The apparent gratitude for what disability has given the women was noticeable, highlighting the positive outcomes of adapting to an acquired disability and demonstrating an appreciation for how adaptive sport experiences and connections within the disability community may facilitate adaptation. This is consistent with an affirmative conceptualization of disability (Swain & French, 2000) that celebrates disability as something that enriches life rather than viewing it as a misfortune needing to change.

Just as the narratives in this study showed that *having a disability* and *being disabled* is a product of the interaction of individual, environmental, and social factors, the women's stories also captured internal, environmental, and social factors that play a role in *living with disability*. This aligns with existing conceptualizations of *living with disability* that indicate that adaptation to acquired disability is a multidimensional process affecting a wide range of physical, psychological, environmental, and social life domains (Bishop, 2005; Devins & Shnek, 2000;

Kendall & Buys, 1998; Livneh, 1986, 2001). As shown through the four narrative types, women had to navigate the biological realities of their bodies to manage their daily lives effectively while also considering the accessibility of their environment. The women also recounted the challenges of interacting with nondisabled individuals while emphasizing the transformative impact of their connections within the disability community.

The contemporary literature on *living with disability* remains inconclusive on whether adaptation to acquired disability has an eventual final adaptation outcome or is a continued process of adaptation throughout the lifespan (Livneh, 1991; Vash & Crewe, 2003). The narratives in this study seem to support the latter, as it was evident that regardless of the time since SCI, none of the women had yet reached a final outcome in their narratives. In fact, multiple narratives described the new, renewed, or ongoing challenges associated with aging with a disability. Experiences related to an aging body, changing relationships, and withdrawal from involvement in the disability community created obstacles that tested the women's ability to continue to live with a disability. The women's adaptation was shown to be contingent upon the continued interplay between their coping resources, the evolving nature of *having a disability*, and their relationship with the social environment.

The women's narratives also showed that *living with disability* is similar to *being disabled* as it was shown to be a process strongly shaped by the relationships with both disabled and nondisabled individuals. The women experienced challenges in trusting nondisabled individuals to understand their impairment needs, often hindering their ability to form romantic relationships. The women also found it difficult to ask for help and accept reliance on people without disabilities, as many valued independence and feared being a

burden. In fact, trusting others with their needs and accepting assistance remained a challenge throughout the women's narratives, a finding that aligns with cultural narratives that promote rugged individualism, emphasizing self-reliance over government assistance (Bazzi et al., 2020). The narratives also demonstrated how the women's relationships with women athletes with disabilities became essential in facilitating entry into adaptive sport and providing insights into navigating life with a disability. These connections offered shared knowledge and experiences that helped normalize disability and highlighted possibilities for women with disabilities, thus exemplifying that "seeing is believing" and inspiring the women to realize their potential.

In summary, the four narrative types in this study suggest that *living with disability* is characterized as (a) a challenge to overcome, (b) having the potential for positive outcomes, (c) being a multidimensional process, and (d) being an ongoing journey. The key factors that affected the process included (a) the relationships with both disabled and nondisabled individuals and (b) athletic identity. The findings align with contemporary literature (Kendall & Buys, 1998; Olkin, 1999) that suggests *living with disability* is a continued process of adaptation throughout the lifespan that is contingent upon the interplay between internal and external factors.

6.5.5. Limitations

The narrative inquiry approach (Riessman, 2008) provided rich, in-depth insights into the complexities of the women's experiences within the context of their lives, giving a more holistic understanding of the phenomena. However, presenting the narratives in written form also constrained the storytelling of the women's experiences. As this study aimed to categorize individual narratives into shared narrative types, many valuable nuances in the women's stories

could not be fully captured. Instead, the narratives presented illustrate key aspects of the women's stories that the researcher determined were most relevant and meaningful to the constructed narrative types. The study's reliance on women's spoken narratives to interpret and understand their lived experiences can be considered both a strength and a limitation. Although this method can yield valuable insights, it has been suggested that many aspects of a person's lived experience are not easily expressed or interpreted through spoken or written words (Kirova & Emme, 2006). The cross-sectional study design can also be considered a limitation – while the women shared stories grounded in past experiences with acquired disabilities, their personal narratives are ultimately embodied in the present. Therefore, their present embodiment influenced how they interpreted their past experiences. Equally, consistent with foundational research (ED & NSF, 2013), caution is warranted when applying the findings to different populations or developing practice recommendations, given the specific sample and methodology used.

6.5.6. Future Research

The findings from this study extend existing research and theory by capturing how women athletes with disabilities exhibited autonomous agency in their experiences of *having a disability*. Future research may explore how individuals with disabilities exercise their social agency and how this affects the construction of meaning associated with *having a disability*. The results also highlighted the significance of relationships with both disabled and **nondisabled** individuals in shaping the meaning associated with *being disabled* and *living with disability*. Future research is encouraged to investigate how the people surrounding individuals with acquired disabilities influence their disability identity development and the process of

adaptation. Specifically, it is important to examine the role of disability status, value systems, and shared social narratives in this process. Do these external influences lead individuals to cling to the past, or do they inspire them to create new narratives and move forward? Another area for future research is examining how women continue to adapt to acquired disabilities as they age. This study found that the experience of *living with disability* did not culminate in a clear final adaptation outcome; instead, aging introduced various factors that complicated and challenged individuals' ability to manage their disabilities. This prompted them to reconsider their approaches to *living with disability*, often resulting in difficult decisions. Finally, to capture meanings that cannot be adequately conveyed through narrative alone, future research could adopt an approach that incorporates visual media, such as Photovoice (Wang & Burris, 1997). This may enable researchers to uncover deeper meanings that can enhance our understanding.

6.5.7. Practical Implications

As this study is foundational research, the outcomes include advances in understanding important constructs that could serve as a basis for future studies; it should not directly influence applied practice (ED & NSF, 2013). When coalesced with existing theory and evidence, the study's findings emphasize the role of disability stigma and self-stigma in constructing the meaning of *having a disability* and *being disabled*. To combat stigma and promote positive conceptualizations of *having a disability* and *being disabled*, rehabilitation professionals could incorporate patient education messaging that fosters an affirmative understanding of disability, showcasing the potential for enrichment in the lives of women with disabilities.

6.5.8. Conclusion

Acquiring a SCI has significant implications for women athletes, as they face distinct societal challenges while adapting to acquired disability. Despite the existing body of research on the psychosocial adaptation experiences of athletes who acquire a SCI (see Zike et al., 2024), research on the acquired disability experiences of women athletes has remained limited. Findings from the current study identified four types of disability narratives of women athletes after SCI and documented the meanings they attributed to *having a disability*, *being disabled*, and *living with disability*. These narratives demonstrated the unique challenges women athletes face after SCI, as having a disability was shown to affect their experiences of womanhood and how they negotiated their athletic identity. The narratives also highlighted the collective nature of the acquired disability experience while also demonstrating the uniqueness of the women athletes' personal narratives of disability. The meaning derived from the women's narratives illustrates the intersecting relationship between *having a disability*, *being disabled*, and *living with disability*. Consequently, it emphasizes the importance of understanding each of the constructs and how they intersect when investigating psychosocial adaptation experiences of acquired disability.

Chapter VII: Study Two

7.1. Abstract

A recent systematic review has highlighted the apparent lack of research on the psychosocial adaptation experiences of women athletes with spinal cord injuries (SCIs; Zike et al., 2024). This gap in research is problematic, as these women face distinct societal challenges stemming from overlapping systems of oppression, which significantly influence their daily experiences of adaptation to disability. To gain a deeper understanding of their experiences, it is essential to explore the meanings that women athletes with SCIs attribute to their subjective experiences of acquired disability. This study aimed to give women athletes who have acquired a SCI a visual voice to capture the elements that shape their everyday life experience of (a) *having a disability*, (b) *being disabled*, and (c) *living with disability*. Using a qualitative, exploratory Photovoice approach (Wang & Burris, 1997), six women captured photographic images with personal cameras that illustrated the meaning of acquired disability in their everyday lives. After two weeks of photo-taking, participants completed a virtual semi-structured interview to discuss the meanings represented in the images they captured. The data were analyzed using Tsang's (2020) Photovoice data analysis method. Eight major themes were constructed from the data: (a) *Taking Care of the Disabled Body*, (b) *Continuity and Attachment*, (c) *The Disability Tax*, (d) *Adaptations*, (e) *Interpersonal Connections*, (f) *Environmental Accessibility*, (g) *Feeling Like a Disabled Person*, and (h) *Gratitude*. These themes emphasize the complexity of the disability experience by highlighting it as multidimensional, situational, contextual, and social-relational in nature. The themes also demonstrate the autonomous agency of women athletes as they navigate their daily lives with disabilities. The

meanings derived from the themes illustrate the interconnectedness of *having a disability*, *being disabled*, and *living with disability*, stressing the need to understand these components collectively when exploring psychosocial adaptation experiences related to acquired disability.

7.2. Introduction

There is a significant gap in research regarding the psychosocial adaptation experiences of women athletes who have acquired a spinal cord injury (SCI). Most existing research in this area focuses on the experiences of a largely homogeneous sample of White men (Zike et al., 2024), with only five studies having included women athletes who have experienced a SCI. As a consequence, the unique experiences of women athletes adapting to disability following SCI remain largely unexplored. This gap in research is problematic, as women with disabilities encounter distinct societal challenges stemming from overlapping systems of oppression, such as ableism and sexism (Garland-Thomson, 2001). Additionally, women athletes must navigate restrictive societal standards of hegemonic masculinity and ideal femininity (Krane et al., 2004). Furthermore, women athletes with disabilities must navigate additional obstacles, as the disabled body—frequently perceived as weak, passive, and dependent (DePauw, 1997)—fails to meet the standards of the ideal athletic body (Hardin, 2003). Considering these challenges, it is important to understand the meanings women athletes assign to their experiences of adaptation to acquired disability.

Prior research in this area has primarily employed qualitative research methods (e.g., interviews, narrative analyses, thematic analyses) that prioritize the expression and interpretation of the spoken word or narrative (Zike et al., 2024). Kirova and Emme (2006) have argued that reliance on the spoken or written word or narrative to understand an individual's lived experience is problematic as many elements that constitute one's experience are not easily expressed or interpreted through these traditional qualitative research mediums. Research indicates that visual images can effectively convey meanings that transcend verbal

expression as they can encourage participants to reflexively think, recall, and represent their thoughts and feelings of events captured in a moment (Glaw et al., 2017; Raggl & Schratz, 2004). As such, an approach that incorporates visual media such as Photovoice (Wang & Burris, 1997) can enable research to achieve a richer understanding of the disability experience than through written or spoken narrative alone.

This study examines three aspects of women athletes' experiences of psychosocial adaptation to acquired disability after SCI: (1) having a disability, (2) being disabled, and (3) living with disability. For clarity, in this study, having a disability was conceptualized as the meaning assigned to possessing an impaired body while navigating the world; being disabled was conceptualized as the meaning assigned to disability identity and the effect that has on the relationship with self, others, and the environment; and living with disability was conceptualized as the meaning assigned to the process of adaptation to disability and the factors that influence the process. This study aimed to provide women athletes who have acquired a SCI a visual voice to capture the elements that shape their everyday life experience of (a) having a disability, (b) being disabled, and (c) living with disability in the community. To address this aim, this study sought to answer the following research questions:

1. How do women athletes who have acquired a SCI capture the elements that shape their everyday life experience of having a disability in the community?
2. How do women athletes who have acquired a SCI capture the elements that shape their everyday life experience of being disabled in the community?
3. How do women athletes who have acquired a SCI capture the elements that shape their everyday life experience of living with disability in the community?

7.3. Methods

7.3.1. Design

This study employed a qualitative, exploratory, prospective research design (Creswell & Clark, 2017). Grounded in an ontological belief that reality is multiple, subjective, and socially constructed (i.e., relativism; Guba & Lincoln, 1994, p. 110), along with an epistemological belief that knowledge is constructed through human perception and the interactions between individuals and their social and cultural environments (i.e., constructionism; Sparkes & Smith, 2014), the Photovoice approach (Wang & Burris, 1997) was considered appropriate to fulfill the study's aims. This approach encouraged the co-construction of meaning through a dialogical interpretation process between the researcher and the participants (Plunkett et al., 2013).

7.3.2. Positionality

The researcher, a White cisgender man with a disability, has a personal history of SCI after becoming quadriplegic in his late teens due to an ice hockey accident. This personal experience influenced his selection of research topic and offered a unique insider perspective regarding disability. His understanding of the SCI experience affected every facet of the research process. The researcher's insights enhanced the study by shaping its conceptualization, guiding the choice of data collection methods and construction of research tools, and improving the analysis and interpretation of participants’ accounts. Reflecting on the research process, the participants often viewed him as an insider during interviews, which built a sense of familiarity, trust, and rapport. Participants often mentioned that his shared experience with SCI made them feel more comfortable when discussing information they might not disclose to someone without that experience.

7.3.3. Participants

Participants were self-identified women who acquired a SCI and, as a result, have a physical disability (N = 6, M_{age} = 35.5 years, SD = 14.29, age range =19–54 years, $M_{\text{age at injury}}$ = 24 years, SD = 9.36, age at injury range = 17–42). Three reported a complete SCI and three reported an incomplete SCI. The six women in this study were all self-identified athletes who had participated in sport for several years (M = 13.67, SD = 4.27, range = 8–22) before their respective SCIs. In this study, sport was defined as a (a) freely chosen, voluntary activity that is (b) governed by rules (i.e., constitutive rules, rules of decency, and fair play), (c) physically challenging, and (d) involving competition in a mutual challenge to achieve excellence (Boxill, 2003). See Table 5 for participant demographics.

Table 5

Study Two Participant Demographics

Participants	**Age**		**Level of SCI**	**Type of SCI**	**Completeness of SCI**	**Athletic Identity at SCI**	**Years in Sport Before SCI**	**Race**
	SCI	Interview						
Angela	42	52	C5/C6	Sport	Complete	Yes	22	White
Chelsea	17	19	L1	MVA	Incomplete	Yes	14	White
Gillian	24	28	C6	Medical	Incomplete	Yes	11	White
Julia	24	27	T6	Sport	Complete	Yes	8	Native Hawaiian
Kendall	17	54	T11/T12	Fall	Complete	Yes	13	White
Miranda	20	33	C5/C5	MVA	Incomplete	Yes	14	White

7.3.4. Instruments

7.3.4.1. Camera. All six participants used personal devices (e.g., camera phones, digital cameras) to capture photographic images related to acquired disability in their everyday lives. Participants who could not use the camera themselves were advised to direct someone else to take photographs on their behalf, under their supervision. To maintain consistency in data collection, participants were instructed to take at least one photo of each theme (see 7.3.4.2), resulting in a minimum of five photos, and no more than 27 photos.

7.3.4.2. Photograph Guidance. Participants received photograph guidance (see Appendix D) to take images that highlight specific themes: (a) what it means to have a disability, (b) what it means to be a woman with a disability, (c) what it means to be a woman athlete after a spinal cord injury, (d) what makes (or does not make) one feel like a disabled person, and (e) what has shaped one's experience living with disability. The themes included in the photograph guidance were designed to emphasize the elements that shape the everyday experience of (a) *having a disability*, (b) *being disabled*, and (c) *living with disability* in the community. To ensure task clarity, the photograph guidance directed participants to select images of landscapes, objects, people, situations, and symbols that best represent these themes. This guide also included instructions on what to incorporate into the participant's written narrative for each image.

7.3.4.3. Electronic Logbook. Participants utilized electronic logbooks to document additional insights and details during their picture-taking sessions. Each participant was granted access to a private electronic logbook within a Microsoft TEAMS folder. They were instructed to write a brief narrative of 2–3 sentences that described the image and provided context for each

photograph they took, including details about its significance. The use of logbooks aided in preserving perspective and context prior to the photo-sharing interview. The researcher reviewed the logbooks to make initial interpretations ahead of the interview. Participants facing physical challenges that made completing the electronic logbook difficult were permitted to seek assistance with writing.

7.3.4.4. Semi-Structured Interview Guide. A semi-structured interview guide (see Appendix E) was utilized in online photo-sharing interviews to ask questions related to participants' interpretations of the photographs. Adapted from key components of the SHOWeD technique (Wang & Burris, 1997), the questions in the interview guide explored the elements that shape participants' everyday life experiences regarding (a) *having a disability*, (b) *being disabled*, and (c) *living with disability* in the community. The guide included primary questions designed to extract participants' descriptions and interpretations (e.g., "What is meaningful to you about this photograph?", "How does this photograph illustrate what has shaped your experience living with disability?"). The questions were open-ended, focusing questions that were framed in everyday language. This type of questioning allowed participants the flexibility to respond openly without being directed on what to address (Smith, 1995). Prompts were employed to supplement the interview guide and elicit rich data, giving participants opportunities for explanation and elaboration (Sparkes & Smith, 2014).

7.3.4.5. Field Notes. The researcher utilized field notes (Patton, 2002) throughout data collection to document thoughts and self-reflections, while also engaging in reflexivity regarding various aspects of the research (van Manen, 1997). This tool facilitated interpretation by retaining contextual details and immediate reflections. The field notes were employed both

during the initial review of participant images and after the online semi-structured interview conducted in this study.

7.3.5. Procedures

7.3.5.1. Recruitment. Participants were recruited through purposive and snowball, convenience sampling (Frost, 2021). As part of a larger research project, contact was made initially with the participants via collaborating sites (i.e., SCI Model System Centers, Wisconsin Adaptive Sport Association) that facilitated the distribution of a email invitation with a hyperlink to an eligibility survey on Qualtrics. Once determined eligible and upon giving informed consent, six women who acquired a SCI and, as a result, have a physical disability agreed to participate in the study. The researcher emailed participants using a second contact script (see Appendix N) to schedule a one-on-one, face-to-face, virtual introductory session prior to data collection.

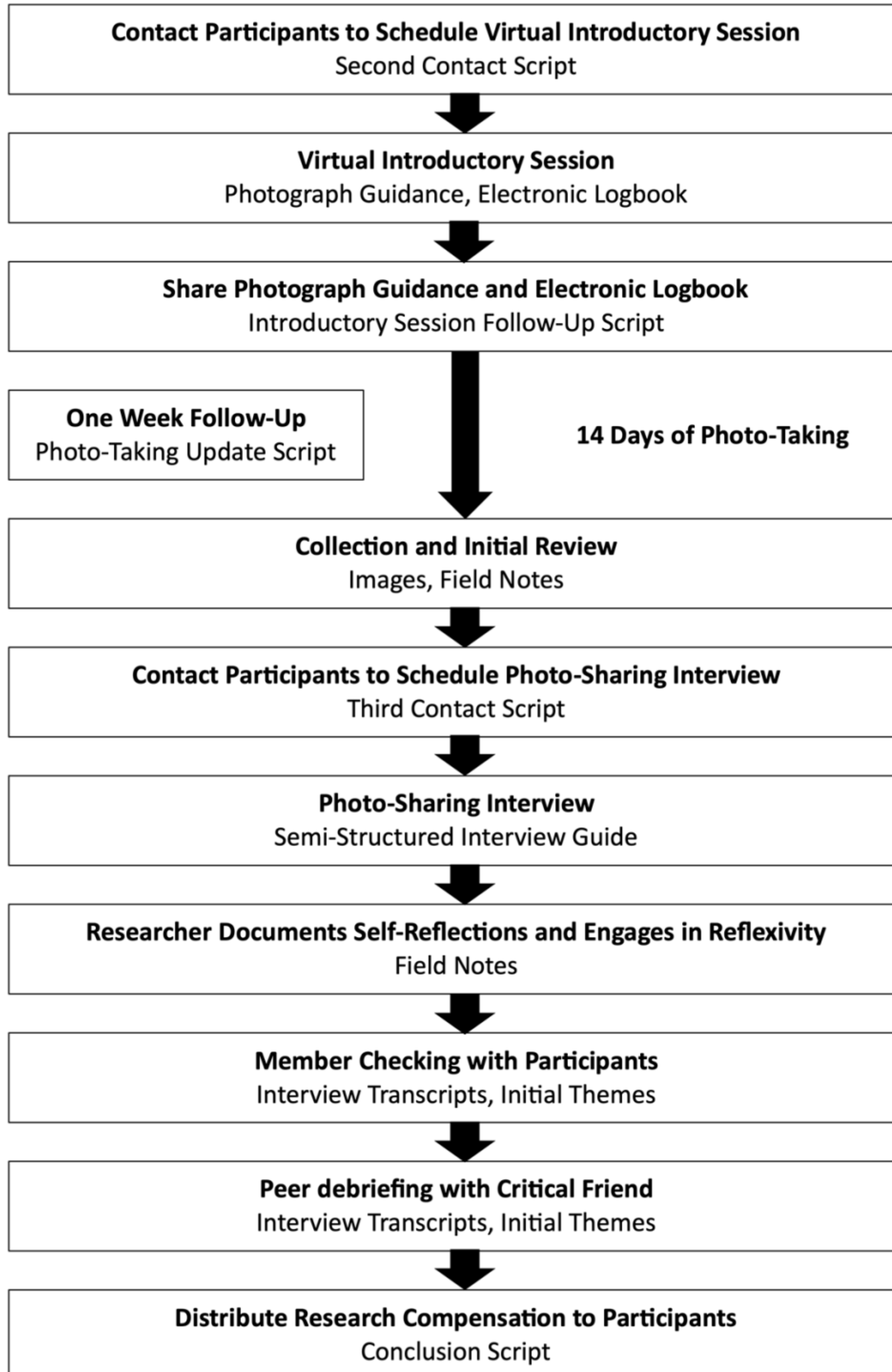
7.3.5.2. Data Collection. Data were collected in the form of photographs taken by camera, written narratives inside electronic logbooks, and semi-structured interviews. In a virtual introductory session, the researcher outlined the Photovoice process and provided basic training on using a camera to take photographs. After the session, the researcher emailed participants using the introductory session follow-up script (see Appendix O) to share photograph guidance and instructions on accessing and inputting data into an electronic logbook. Participants had two weeks to take photographs. After the first week, the researcher called participants using the photograph update script (see Appendix P) to discuss and encourage photo-taking and electronic logbook entry. After completing their photo-taking, participants uploaded their images to a private Microsoft TEAMS folder. A total of 79 images

were captured by the participants (*M* = 13.17, *SD* = 10.05, range = 5–27). Subsequently, the researcher emailed participants with a third contact script (see Appendix Q) to arrange a photo-sharing interview.

Semi-structured interview data were collected through virtual, face-to-face photo-sharing interviews with each participant through video call software (i.e., Microsoft Teams). In these online interviews, only the researcher and the participant were present. The researcher and the participants discussed each image in the order in which they were captured. The interviews ranged in duration from 20 to 102 minutes, with an average interview length of 51 minutes (*SD* = 30.95). All interviews were audio and video recorded and transcribed using Glean® and Microsoft TEAMS software. Each interview transcript was checked for accuracy against the interview recording. Participants were given pseudonyms that were used throughout the study. Any identifying information (e.g., names, locations) was replaced or removed from the data, including transcripts, recordings, notes, and photographs. The University of Wisconsin-Milwaukee Institutional Review Board approved this study. See Figure 10 for a flowchart of the study procedures.

Figure 10

Flowchart of Study Procedures



7.3.6. Data Analysis

Using NVivo 15 (Lumivero, 2024), the data were analyzed using Tsang's (2020) novel Photovoice data analysis method, which involves four steps: (a) preview, (b) review, (c) cross-photo comparison, and (d) theorizing. Tsang's (2020) approach resolves the limitations of other Photovoice data analysis approaches by respecting and balancing the researcher's and the participant's interpretations and recognizing participant photographs as inherently meaningful data. The first stage of analysis was a photograph analysis based on the researcher's interpretations in which the content of photographs and narratives taken from the electronic logbooks were categorized into themes. The first stage was carried out before the online photo-sharing interview. The second stage involved a photograph analysis based on the participant's interpretations collected in the online photo-sharing interview. This stage was carried out in much the same manner as the first stage, but it involved seeking alternative explanations to those generated in the previous stage. Next, a cross-photo comparison or "dialogue" between the interpretations of the researcher and participant developed an integrative explanation of the phenomena at a higher order. In the fourth stage, the researcher identified relationships between the themes and generated a combined visual and narrative representation of explanations of the phenomena. At each stage, from one to three, each case was analyzed individually before the researcher gathered master lists and analyzed the data's convergence and divergence.

7.3.7. Methodological Integrity

Strategies were utilized to ensure trustworthiness and reflexivity. The researcher implemented member-checking (Creswell & Miller, 2000) by providing participants with

interview transcripts and initial themes, encouraging them to review these materials and provide their feedback within a two-week period. Participants were invited to assess the interpretations' appropriateness and believability and offer critique or affirmative feedback (Smith & McGannon, 2018). This method was instrumental in verifying whether the data analysis accurately captured the experiences of the participants. The researcher also conducted peer-debriefing (Barber & Walczak, 2009) by sharing transcripts of interviews and a list of themes with a trusted colleague, referred to as a "critical friend." This critical friend examined the transcripts and initial themes, providing feedback on their formulation and proposing alternative interpretive perspectives. Through discussions with this critical friend, the researcher could evaluate the defensibility of their interpretations and determine their plausibility (Smith & McGannon, 2018). The third author acted as the critical friend. A reflexive diary (Clancy, 2013) was part of the field notes gathered throughout the research process. This practice facilitated the recording and contemplation of thoughts and actions during the study, helping to clarify how the researcher’s viewpoints and experiences shaped the study findings. During the project, the researcher and the second author engaged in reflective discussions concerning the study procedures. These discussions promoted self-reflection and conversation about various elements of the research.

7.4. Results

Through a combination of visual and narrative representations, the participants captured several elements that shape their everyday life experience as women athletes with disabilities. These elements were identified in eight overarching themes: (a) *Taking Care of the Disabled Body*, (b) *Continuity and Attachment*, (c) *The Disability Tax*, (d) *Adaptations*, (e)

Interpersonal Connections, (f) *Environmental Accessibility*, (g) *Feeling Like a Disabled Person*, and (h) *Gratitude*. See Table 6 for a list of themes and subthemes with associated photographic images.

Table 6

Photovoice Themes, Subthemes, and Associated Photographic Images

Theme	Subtheme	Associated Photographic Images
Taking Care of the Disabled Body		G2, J5, J13, J17, K2, K3, K4
Continuity and Attachment	Continuing to Participate in Sport	C1, C4, C6, G3, J3, J7, J8, J10, J13, J14, J19, J25, J26, K1, M3
	Like She Used To	A1, A7, A17, A18, A20, C7, J1, J3, J6, J8, J9, J10, J13, J17, J19
	Shedding the Wheelchair	J9, J16, J19, J21, J22, J23, J27
The Disability Tax		A1, C5, J12, K1, K5, G1, G2, M4
Adaptations	Maintaining a Safety Net	A12, A24, K7
	Adapting Activities for Participation	A7, A23, C1, C6, J3, J8, J13, J15, J26, K2
	Using Adaptive Equipment	A24, G1, J1, J2, J4, J7, J10, J19, J21, J25, K1, K6, M3
	Having an Adaptive Mindset	A11, J11, J14, J15, J21, K2, K4, K9
	Relying on Others	A8, A9, A20, A21, A23, A25, K3, K5, M2
Interpersonal Connections	Connecting with the Disability Community	C3, C4, C6, G3, G5, J4, J7, J24, J25, K3
	Navigating Social Interactions and Attitudes	A2, A4, G4
	Social Support	A1, A2, A8, A13, A23, A25, C2, C5, J9, J17, J22, J23, J27
Environmental Accessibility	Accessibility Influences Access and Participation	A9, A11, A14, A19, A20, A21, A22, C5, J4, J9, J10, J11, J12, J16, J17, J18, J20, K5, K6, M1, M4
	Does Accessible Mean Accessible?	G6, J20, K7
Feeling Like a Disabled Person	Having to Adapt and Use Adaptations	A1, A12, J1, J2, J3, J6, J8, J18, K8

	Encountering Inaccessible Spaces	A11, C5, G6, M4
	Salience of Disability	A14, G1, G4, J6, J16, J19, K9
Gratitude		A1, A2, A3, A5, A8, A9, A10, A13, A14, A18, A25, J1, J2

7.4.1. Taking Care of the Disabled Body

The theme of *Taking Care of the Disabled Body* refers to the activities captured by participants that demonstrate how they have cared for, maintained, and accepted their disabled bodies in their everyday lives, allowing them to continue living as they wish. Half of the participants—Kendall, Gillian, and Julia—shared a total of seven images that represent this theme.

Image K2, captured by Kendall, depicts her exercising on her bed at home while recovering from a pressure sore. She explained that it was important to her to keep up with these exercises while caring for her skin so that she could maintain her physical strength for future hand-cycling competitions. In Image G2, Gillian highlighted the functional importance of maintaining her daily routine of using her exercise bike with a functional electrical stimulation cuff:

> You know, it is my choice to do the e-stem bike. I don't have to do it, but in order to kind of keep up my health and my muscle mass and be able to do some of the things I want to do, like walking, it's this extra part of my routine.

Figure 11

Taking Care of the Disabled Body: Images K2 and G2

The need to care for and maintain paralyzed limbs is also reflected in Image J5, capturing Julia's use of a Normatec leg recovery system on her legs. Julia said that instead of only stretching and exercising her upper body, she uses the Normatec leg recovery system to loosen her legs and prevent muscle atrophy. She explained that this represents how she has learned “to take care of all my body, not just what works.” In Image K4, Kendall illustrated how caring for the disabled body goes beyond physical exercise and maintenance by altering her clothing to ensure it fits her body better. She said,

> I think my trying to actually alter clothing to make it fit that body better is a way of doing honor to that body, to that disabled body. You know, clothing it properly is a way of respecting it, I think, and not being afraid to show it for what it is.

Kendall expressed her frustration with the fashion industry, feeling it does not cater to individuals "like me." She felt that, as a woman, she has a heightened awareness of her body, which for a long time made her want to hide her disabled body because of the associated stigma. Her efforts to modify clothing became a way to embrace and celebrate her disabled body.

Figure 12

Taking Care of the Disabled Body: Images J5 and K4

7.4.2. Continuity and Attachment

The theme of *Continuity and Attachment* refers to the images captured by participants that demonstrate their continued participation in and attachment to aspects of their pre-SCI lives. All of the participants—Angela, Chelsea, Gillian, Julia, Kendall, and Miranda—shared a total of 29 images that represent this theme. The *Continuity and Attachment* theme is further

divided into three subthemes: (a) *Continuing to Participate in Sport*, (b) *Like She Used To*, and (c) *Shedding the Wheelchair*. What follows is a brief description of each with associated images.

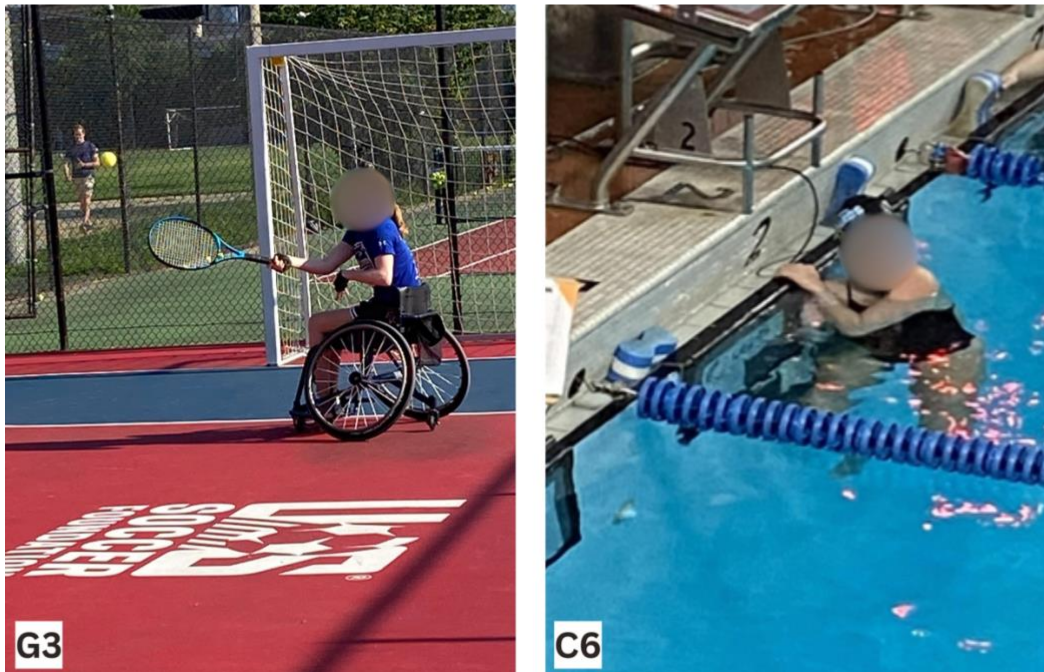
7.4.2.1. Continuing to Participate in Sport. The subtheme of *Continuing to Participate in Sport* refers to the activities captured by participants that illustrate their ongoing relationship with sport, including how that relationship has changed and the benefits of adaptive sport participation. Five participants—Chelsea, Gillian, Julia, Kendall, and Miranda—shared a total of 15 images that represent this subtheme.

The women in the study highly valued their sport participation before SCI and frequently captured representations of what life looked like for them as women athletes after SCI. Gillian highlighted, "This is how sports looks a little different now," with Image G3 representing her swinging a tennis racket from a sports chair on a tennis court. She said that she likes playing wheelchair tennis and believes Image G3 represents how her life as an athlete has changed. Chelsea also captured her experience participating in adaptive sport in Image C6, representing her in a swimming pool holding the wall for support in an adapted start position. She explained why she got involved in adaptive sport:

> I wanted to, like, still be competitive because, like, I'm still young, and like, I definitely would have joined, like, intramural, like volleyball or something. Like, I would have joined some sport in college. So, it gave me an opportunity to still join a sport.

Figure 13

Continuing to Participate in Sport: Images G3 and C6



Julia captured several images, including Image J7 of her participating in sled hockey, that she said were illustrative of what it means to be a woman athlete after SCI, saying, “Yeah, just continuing, again, being an athlete after my accident” and “just continuing doing adaptive sports and trying out new sports.” The women’s adaptive sport involvement shaped their lives after SCI, allowing them to stay close to sport, retain their athletic identity, and have novel sport experiences. As suggested by Image J25, representing four women athletes in sports chairs holding tennis rackets and posing together for a picture, these sport experiences also shaped the women’s lives by connecting them to a community of adaptive sport athletes. Gillian commented on Image G3 that her adaptive sport connections had helped her adapt to disability: “Getting to know the community of other disabled people. Doing adaptive sports is

where I've gotten to know the most other people with disabilities, um, ways of kind of adapting my life after injury."

Figure 14

Continuing to Participate in Sport: Images J7 and J25

In addition to the connections made through adaptive sport, the women shared how their involvement in adaptive sport has helped them adapt to life with a disability. Julia captured how adapting exercises so she could complete them in her wheelchair has helped her: "Hopping down curves, hopping up curves, and going around obstacles in my chair, like, CrossFit has helped a lot with that." Kendall shared that she has also benefited from the routine tinkering that she has to do on her handcycle (as shown in Image K1) to be able to participate in adaptive sport, describing how it has helped her become more adaptive in her everyday life:

> I feel like going through this process day after day, year after year, has sort of trained me to be able to think about how to modify all types of different situations, and to be

creative, and to use whatever materials I can come up with, and try to understand how things work together, and so that's all good.

Figure 15

Continuing to Participate in Sport: Images J26 and K1

7.4.2.2. Like She Used To. The subtheme of *Like She Used To* refers to the images captured by participants that showcase their reclaiming different aspects of their lives before SCI. Half of the participants—Angela, Chelsea, and Julia—shared a total of 15 images that represent this subtheme.

The women made many comments throughout the interviews expressing their satisfaction at being able to do things “like I used to (before SCI).” These experiences were important to them and indicated they had recovered aspects of their pre-SCI lives. Image C7, captured by Chelsea, depicts her swinging a golf club on a driving range from an ambulatory

stance. Chelsea remarked, “I look normal again” in this image. She commented on her determination to reclaim this aspect of her life, saying,

> I had this goal set since I was in the hospital that I'd be able to golf again, no matter, like, how it was, if it was adaptive or not. I didn't care… So, then I just, like, kept saying, like, one day I want to golf again. So, I kept just, like, changing my goal to, like, be able to make it happen.

Similarly, Julia found satisfaction in participating in sport activities she enjoyed before SCI. She captured Image J3, which shows her sitting on a Waveski as she floats on the water. Julia expressed her joy at returning to the water, saying,

> Being in the ocean, and on the water, and surfing, and nobody, like, how can you swim if you can't use your legs? And there's just being an athlete; you figure it out, and you get out there. But, umm, it's not easy, but I love being out on the water like I used to.

Figure 16

Like She Used To: Images C7 and J3

This element of the women's life experiences appeared to signify an attachment to life before SCI and the activities from which they drew satisfaction. In Image J1, Julia captured herself driving her vehicle with adaptive controls. She described her feelings when driving independently: "It just feels like I'm driving like I used to." Angela shared Image A7, which depicts her playing Scrabble with a friend. She expressed how meaningful it was for her that (a) her hands functioned well enough to maneuver the tiles herself, (b) she could continue participating in an activity she enjoyed before SCI, and (c) she could share the experience with a friend. She highlighted the significance of this activity by contrasting it with what she lost since her SCI (i.e., nondisabled cycling): "I am missing out by not being able to ride bicycles, and missing out on the social aspect that I used to have with my fellow cyclists."

Figure 17

Like She Used To: Images J1 and A7

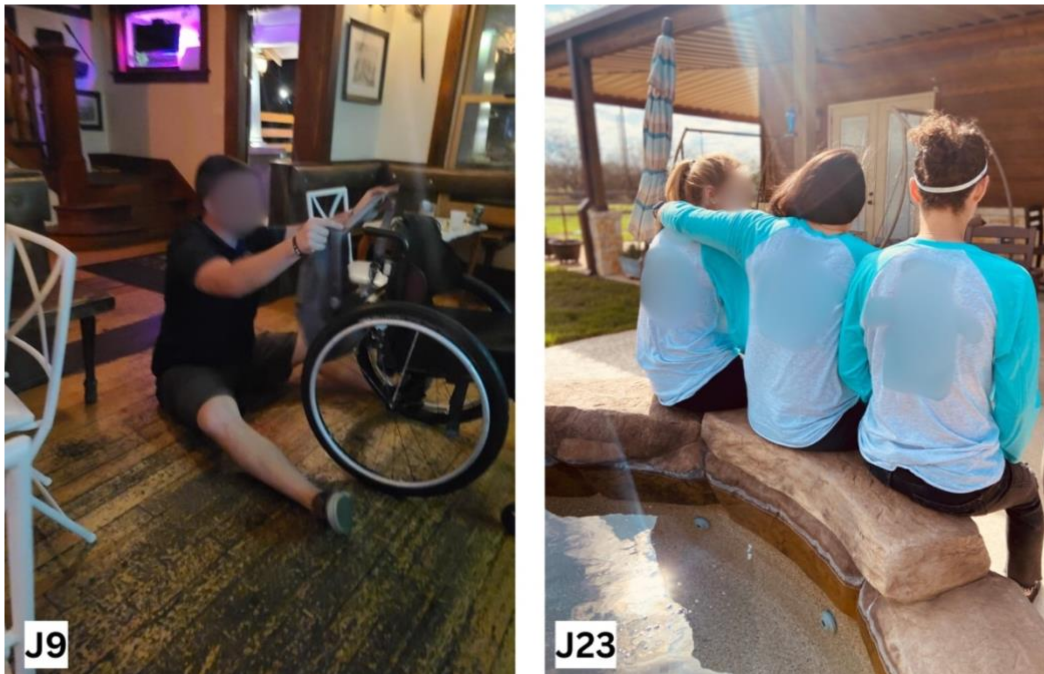
7.4.2.3. Shedding the Wheelchair. The subtheme of *Shedding the Wheelchair* refers to the images captured by a participant that demonstrate their predilection for getting out of their wheelchair and engaging in activities without it. One participant—Julia—shared a total of seven images that represent this subtheme.

Julia's images and narrative commentary express her enjoyment and desire to leave her chair whenever possible. Image J9 shows Julia capturing her nondisabled friend laughing while playing with her wheelchair; she is not in the image as she explained that she took the image from where she was seated on a couch. Discussing Image J9, she remarked, "I always like to get out of my chair when I can." This became evident when reviewing the images she captured. When discussing Image J23, which depicts her posing for a photograph with two of her friends, she said, "I always get out of my chair for photos." In the images presented in this theme, she

appears to convey a preference for being seen for who she is without her wheelchair. The juxtaposition of her presence in the wheelchair in other themes, usually to participate in sport activities, against her evident wish to evade the gaze of others suggests a complex relationship with her mobility device, which could symbolize both freedom and the burden of being visually identified by it.

Figure 18

Shedding the Wheelchair: Images J9 and J23



Commenting on Image J19, which shows Julia ready to swing a golf club from a standing position in an adaptive mobility cart designed for standing at a driving range, Julia said, “We were just cruising along in that thing and golfing. And I didn't have to use my chair, so it was pretty nice.” To not “have to use” her wheelchair was a common phrase Julia used when discussing activities that brought her satisfaction. These statements suggested that she was dissatisfied with the need to utilize a wheelchair and was experiencing difficulty integrating it

into her embodied existence. Julia emphasized her dislike for the social expectation that she sit in accessible wheelchair seating at events when discussing Image J16, representing her chair sitting in an accessible seating space marked by a wheelchair sign:

> I just feel like that's where I have to go, and that's where I have to pull up my chair, and I like going out of my chair. I don't like sitting in my chair, but, like, sometimes people just assume, like, I don't know, that I wanna roll up and just chill there. But I don't.

Figure 19

Shedding the Wheelchair: Images J19 and J16

7.4.3. The Disability Tax

The theme of *The Disability Tax* refers to the images captured by participants that demonstrate the added labor and costs that they must pay to go about their daily lives due to having a disability. The women's accounts of these images illustrate how this additional labor often goes unnoticed by the nondisabled, creating further obstacles that hinder their full

engagement with the community. All of the participants—Angela, Chelsea, Gillian, Julia, Kendall, and Miranda—shared a total of eight images that represent this theme.

Chelsea commented on Image C5, which depicts the doors of a Planet Fitness that lack automatic buttons, saying, "It's meaningful because a lot of people don't realize, like, you go through your day without a lot of things being accessible, like, a lot of things aren't." Kendall captured a similar experience in Image K5, which shows Kendall at a supermarket checkout counter with a screen reader positioned too high for her to read, forcing her to depend on another person to press the buttons for her. She commented on the photo, stating, "It illustrates just the, again, yeah, the ways that having a disability means, uh, the small challenges on a daily basis that are not there for most people." The women emphasized that many people overlook or simply do not experience these daily challenges that cost them extra effort to overcome.

Figure 20

The Disability Tax: Images C5 and K5

In addition to the environmental challenges that create extra work for women as they navigate the community with a disability, there is also the need to use adaptive equipment, which can create an additional financial burden. In Image J1, Julia is driving a vehicle equipped with adaptive hand controls, which she had to pay for: “It gets into the $20,000. So, it's pretty expensive, and that's how a lot of disabled people have to pay a lot to get things that help them move about their daily lives.” Gillian illustrated the added time and effort required to use adaptive equipment in Image G1, which shows a collection of braces, crutches, and shoes arranged on the floor beside Gillian’s bed. Gillian explained the added effort that she must expend on these devices to go about her day,

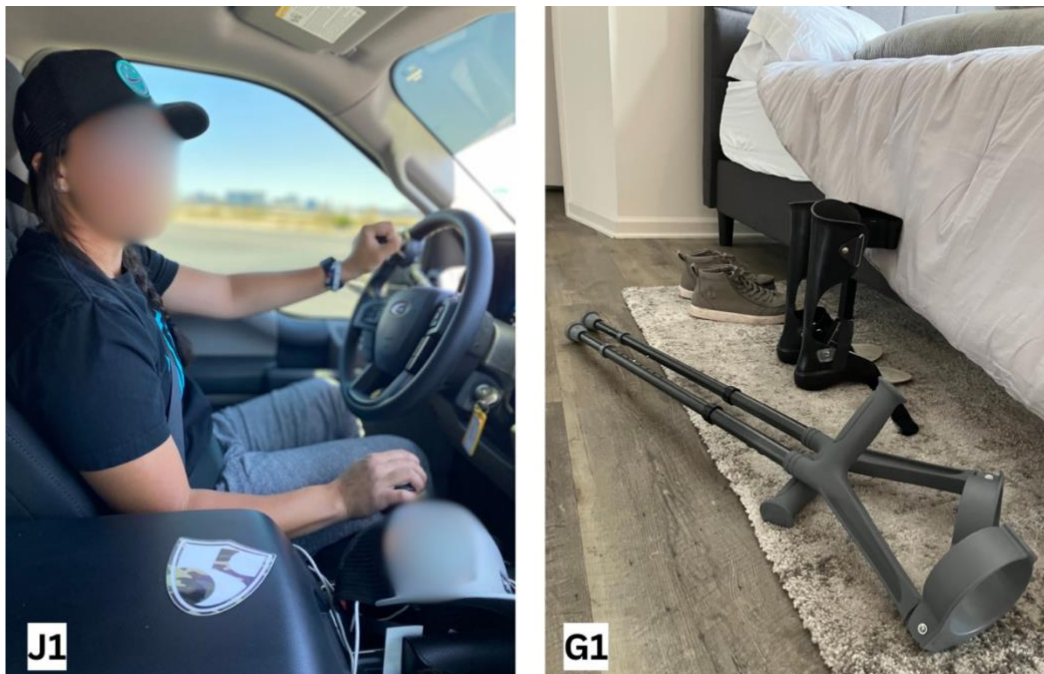
> Just needing additional devices or time; there's always something extra. You know, I can't just get up and go like most other people and run out the door. It's like I have to go

put on the braces and put on the shoes and take the crutches and then go, and even like with the braces, people would think that would be easy, but it's. I had to, like, find special shoes that fit over the braces, you know, and like, things like that. So, there's always just this layer of time and effort involved, I think, in having a disability.

Gillian continued, saying, “There's sort of the behind-the-scenes aspect” of using this adaptive technology that her nondisabled friends and other nondisabled people would not understand and do not see.

Figure 21

The Disability Tax: Images J1 and G1



Kendall demonstrated the additional technological labor involved in maintaining her adaptive sport equipment in Image K1. She explained that, even as a Paralympic-level disabled hand cyclist, she does not have access to the “fit kit system” that nondisabled athletes use, so she must make "do-it-yourself" adjustments to her handcycle: “There is so much other work

that I have to do, umm, simply because there's not easy solutions out there for us.” She mentioned that she has to do all this extra “behind-the-scenes stuff” in her garage, and “no one knows about or really cares about or sees, you know, and it takes a lot. It takes a lot out of me.” Gillian also shared Image G2, which depicts her using her exercise bike with a functional electrical stimulation cuff. She explained that this is an additional aspect of her routine that she has to consider and plan for: “It’s my choice to do the e-stem bike. I don't have to do it, but to keep up my health and my muscle mass and be able to do some of the things I want to do, like walking.”

Figure 22

The Disability Tax: Images K1 and G2

7.4.4. Adaptations

The theme of *Adaptations* refers to the images captured by participants that demonstrate the various ways they have adapted to navigate disability in their daily lives. All of

the participants shared a total of 38 photos that represent this theme. The *Adaptations* theme is further divided into five subthemes: (a) *Maintaining a Safety Net*, (b) *Adapting Activities for Participation*, (c) *Using Adaptive Equipment*, (d) *Having an Adaptive Mindset*, and (e) *Relying on Others*. What follows is a brief description of each with associated images.

7.4.4.1. Maintaining a Safety Net. The subtheme of *Maintaining a Safety Net* refers to the images captured by participants that illustrate various ways they created a safety net of resources and contingencies to handle challenges in their daily lives. Two participants—Angela and Kendall—shared a total of three images that represent this subtheme.

Kendall captured how she stores resources, such as catheters, “all over the place” to ensure her needs are met in most situations while navigating the community. This is illustrated in Image K7, which shows the inside of her car door with an accessible parking placard and catheters in the door pocket. She explained the lengths she goes to guarantee her essential catheterization needs are met:

> I have some in my purse. I have some in my car. I have some, like, in my backpack and some at home, of course, just because without a catheter, I'm screwed. I can't go to the bathroom. I can't empty my bladder.

Likewise, Angela shared that she keeps chargers for her power wheelchair stored in different locations, including at her workplace, to ensure her chair’s battery life meets her daily travel needs. This is depicted in Image A24, which shows the controls of her power wheelchair along with a battery life indicator. Angela expounded on the need to maintain this safety net:

> Yeah, you can't just go out and do something. You've got to plan. If you want to get it done, you have to plan to figure out how that's going to happen, and often not just one

plan, but also a backup plan. Cause your plan A doesn't always work, and so you got to have a backup plan to make sure that you know you're not late for a meeting or miss out on an activity because your plan A didn't work.

Figure 23

Maintaining a Safety Net: Images K7 and A24

Without these resources and contingencies in place, the women may have difficulty participating in the community. This strategic planning can take its toll on one's life, as Angela explains,

> I find myself mapping out my daily life to the… practically to the minute, and it's… I'm not going to say it's lost all of its spontaneity, but I do find myself planning everything so that I can accomplish what I want to accomplish.

7.4.4.2. Adapting Activities for Participation. The subtheme of *Adapting Activities for Participation* refers to the images captured by participants that illustrate the different ways

they adapted activities to facilitate their involvement. Four participants—Angela, Chelsea, Julia, and Kendall—shared a total of 10 images that represent this subtheme.

In Image C6, Chelsea is depicted in the pool, demonstrating a modified swimming start position. She emphasized how adaptations in the sport have allowed her to participate despite her leg weakness. Chelsea explained that this image was significant as it symbolized the achievement of her goals in swimming despite this not being the "normal" way to start. The women also captured images that illustrate how they adapted exercises to stay physically active, as seen in Image J8, which features Julia participating in an adaptive CrossFit competition, using an assault bike in a modified position with attachments and support from a trainer.

Figure 24

Adapting Activities for Participation: Images C6 and J8

These exercise modifications included altering how they used gym equipment and finding creative alternatives to utilize exercise equipment when they could not engage in traditional workouts. This is reflected in Image K2, which shows Kendall attaching resistance bands to her bedframe to continue exercising while recovering from a pressure sore. Chelsea emphasized that "You can still work out; it just might look different than others." Angela shared that she has needed to figure out how to adapt in order to continue doing what she considers basic activities (e.g., getting her haircut). This is illustrated in Photograph A23, which shows her reclined in her wheelchair with her hair in the basin of a hairdresser's sink. She explained that she and the hairdresser had to work together to find a solution since she could not use the basin in the same way as others. The various adaptations captured by the women demonstrate how they have discovered ways to keep engaging in meaningful activities.

Figure 25

Adapting Activities for Participation: Images K2 and A23

7.4.4.3. Using Adaptive Equipment. The subtheme of *Using Adaptive Equipment* refers to the images captured by participants that illustrate the various ways they utilized adaptive equipment (i.e., mobility devices, adaptive sport equipment) to enhance their independence and expand their opportunities. Five participants—Angela, Gillian, Julia, Kendall, and Miranda—shared a total of 13 images that represent this subtheme.

Angela and Gillian took photos of their mobility devices and talked about their reliance on adaptive technology for getting around. Angela shared Image A24, which represents the controls of her power wheelchair. She expressed that this image of her wheelchair symbolizes both "freedom and lack thereof, and the need for planning." She is grateful for her wheelchair and what she is able to do with it, but she also acknowledges the limitations of technology and recognizes the necessity of organizing her life to manage it effectively. Gillian shared Image G1, which shows her shoes, braces, and crutches on the floor beside her bed. She believed that part of what it means to have a disability "is needing to use mobility aids to get around."

Figure 26

Using Adaptive Equipment: Images A24 and G1

These mobility devices have enabled these women to navigate their communities. In Image J1, which shows Julia driving a vehicle with adaptive hand controls, Julia conveyed what this adaptive equipment means to her: "How I can be independent going places I need to. I don't have to rely on other transportation, ADA transportation. I can just get in and go whenever I want on my own time." Kendall and Miranda both took photos of adaptive handcycles. Image M3, captured by Miranda, depicts a handcycle that has not been fully assembled, still resting in the box it was shipped in. Miranda was excited about her new handcycle because she had never had access to such equipment before. This handcycle would allow her to enjoy outdoor activities in ways her wheelchair could not accommodate. Miranda emphasized the significance of this moment, sharing that she had tried various types of handcycles but found they did not meet her needs. She applied for grant funding from multiple

foundations, received those grants, and saved enough money to purchase this handcycle before finally ordering it and waiting six months to receive it. After such a lengthy process, Miranda finally had the handcycle that would enable her to be more adventurous and explore the numerous trails in her community.

Figure 27

Using Adaptive Equipment: Images J1 and M3

7.4.4.4. Having an Adaptive Mindset. The subtheme of *Having an Adaptive Mindset* refers to the images captured by participants that illustrate their adaptive thinking to overcome obstacles and remain open to new experiences. Half of the participants—Angela, Julia, and Kendall—shared a total of eight images that represent this subtheme.

The women shared images that illustrate their resilience in adapting to the challenges they face in the community. Angela shared Image A11, depicting an open cabinet filled with food that is out of reach. She explained that this photo shows how the world is not entirely

accommodating to her, and if she wants something from the top shelf when no one is around, she will find a way to make it work regardless. Kendall echoed this resilient attitude when commenting on Image K9, which captured Kendall trying to keep a bottle of laundry soap from falling off her lap as she exited the grocery store. She expressed her feelings about the situation shown in the image:

> I feel like I don't, you know, like I don't have my stuff together. I don't have, but I'm trying to. I'm trying to do more than I really comfortably can, but I feel like that's a very common part of my daily life too, is like trying to do stuff that, uhm, is just not very easy or workable. And yet, you know, I try to do it anyway, you know?

Figure 28

Having an Adaptive Mindset: Images A11 and K9

The stick-to-itiveness that Kendall demonstrates is evident in her daily activities and her pursuit of goals, as suggested by Image K2, which shows her using a resistance band to exercise

while lying in bed. She said this photo shows, “I'm committed to training even when I'm laid up,” and “I've used my creative powers, as it were, to figure out a solution to keep pursuing my goals, no matter what obstacles are in my path.” The women also captured images that demonstrated how possessing an adaptive mindset involves maintaining an openness to trying new things and exploring opportunities in their community. In her comments on Image J14, which depicts Julia sitting next to an archery target with arrows in it, Julia explained that trying new activities was meaningful to her because, as a wheelchair user, she had been uncertain about the sport opportunities available to her. Realizing she could participate in activities like archery has shown her that she has more options for enjoyment than she was aware of before.

Figure 29

Having an Adaptive Mindset: Images K2 and J14

Julia said, “I'm always willing to figure it out and try something new.” She demonstrated this attitude in several images where she tried different sports as a wheelchair user, including

Image J15, which depicts Julia rock climbing. Kendall felt proud of herself for trying something new when she attempted to alter her pants for a better fit. This is illustrated in Image K4, which shows a pair of jeans with pins in them next to a sewing machine. She believed that her attempt at learning new skills and not being afraid to try things represents her taking charge,

> Yeah, taking control in that way. Umm, instead of just reacting to whatever pants are on the shelf and all I've got to put up with it and wear them, and that's that, you know. It's like taking more, taking the initiative, taking it into my own hands, and doing something about it.

Her willingness to try new things gave her a sense of control over her bodily autonomy. This openness enabled her to be more adaptable, just as Julia's willingness to embrace opportunities allowed her to adapt and engage in new activities.

Figure 30

Having an Adaptive Mindset: Images J15 and K4

7.4.4.5. Relying on Others. The subtheme of *Relying on Others* refers to the images captured by participants that illustrate their experiences of asking for and relying on the help of others in the community. Half of the participants—Angela, Kendall, and Miranda—shared a total of nine images that represent this subtheme.

Angela shared an image of her weekly grocery shopping experience, as seen in Image A8, which captures a grocery store employee reaching for an item in front of her. She expressed her gratitude for the assistance she can call upon when needed: "I can ask somebody to assist me, and there's always somebody who's willing to help me shop so that I can reach the things that otherwise I can't reach." Angela explained that learning to ask for help was initially challenging after her SCI, but she has since stopped hesitating. She said that she has learned that, for the most part, people are willing to help. In a similar situation, Kendall captured Image K5, showing herself at the supermarket checkout with someone pressing the buttons on the screen for her. She said that the screen was too high for her to read, so she asked her daughter to complete the transaction. Kendall explained that, although asking for help is not easy due to the mixed reactions she receives when she does, it can be a powerful tool for achieving what you want:

> Being able to ask for help from others can allow one to, you know, function better, do more, get through hurdles. So, being able to ask for help is sort of like a superpower, I think, for those of us with disabilities.

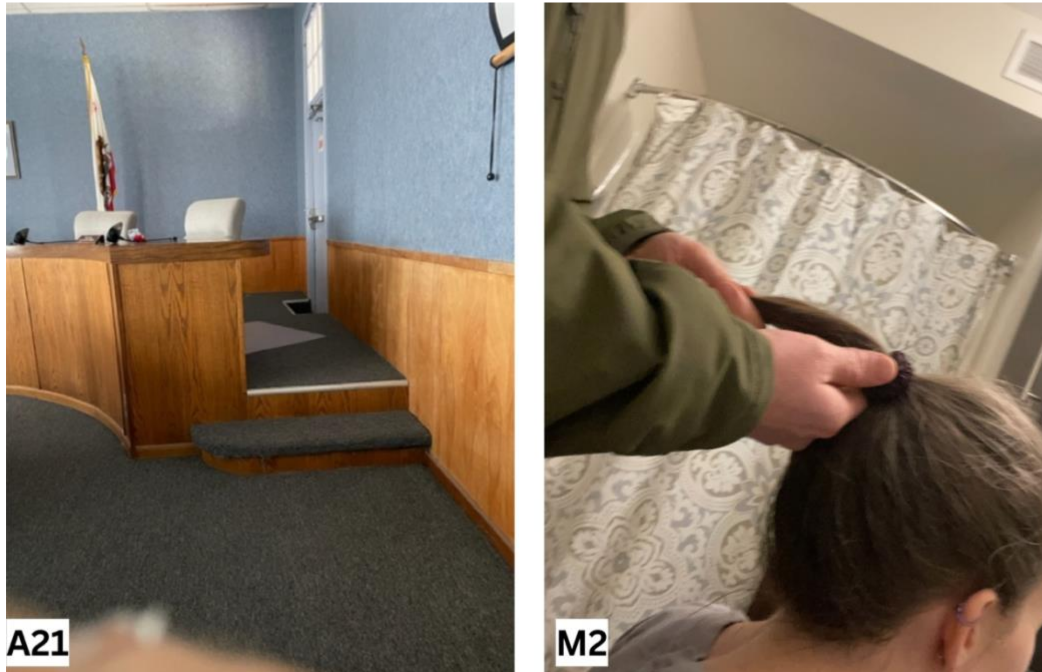
Figure 31

Relying on Others: Images A8 and K5

Additionally, Kendall expressed her “utilitarian” attitude toward asking for help from nondisabled people, stating that they are tools to use: “They're two arms and two legs, and that can help me out a lot.” Angela shared a similar attitude when discussing Image A21, which depicts a pair of steps separating her from the seating area and light switch, simply stating that every time she enters this room, she must ask someone to turn the lights on for her. Miranda shared her experience guiding her partner in assisting with daily tasks, as illustrated in Image M2, which depicts her partner helping her tie her hair into a ponytail. She explained that, as someone with a disability, there are specific tasks with which she requires assistance. She said, “That's not a bad thing. It just is.”

Figure 32

Relying on Others: Images A21 and M2



7.4.5. Interpersonal Connections

The theme of *Interpersonal Connections* refers to the images captured by participants that show how their relationships with the disability community and interactions with nondisabled individuals have shaped their daily lives. Five participants—Angela, Chelsea, Gillian, Julia, and Kendall—shared a total of 25 images that represent this theme. The *Interpersonal Connections* theme is further divided into three subthemes: (a) *Connecting with the Disability Community*, (b) *Navigating Social Interactions and Attitudes*, and (c) *Social Support*. What follows is a brief description of each with associated images.

7.4.5.1. Connecting with the Disability Community. The subtheme of *Connecting with the Disability Community* refers to the images captured by participants that illustrate their relationships with other members of the disability community and the connections they

developed through adaptive sports. Four participants—Chelsea, Gillian, Julia, and Kendall—shared a total of 10 images that represent this subtheme.

The women found their connections with the disability community valuable in numerous ways. These connections assisted them in adapting to their disabilities, developing a social network, and discovering valuable opportunities. Chelsea expressed that her relationships with other women with disabilities on her swimming team and at the “disability gym” she attends make her feel part of a community that comes together to create a feminine, encouraging atmosphere of support for each other. Her experiences on her swimming team have assisted her in making friends and connecting with others, as depicted in Image C4. This image captures an Instagram story sharing her teammate’s news story and includes a caption expressing her gratitude that they are teammates.

The women indicated that they enjoyed and benefited from being around individuals with shared disability experiences. Gillian highlighted her connections within the disability community, particularly with individuals she met through wheelchair tennis. Image G5 depicts her alongside three others playing wheelchair tennis in sports chairs on a tennis court. Gillian emphasized how much she values the time she spends with other people with disabilities and the conversations they have:

> One of the big things that shaped my experience living with disability has been the other disabled people. So, whether that was like when I was going through rehab or like now playing adaptive sports, um, one of the biggest things like advice that I've gotten are ways that I've learned or tips that I've picked up has been through meeting other disabled people.

Similarly, Julia presented Image J25, representing her playing wheelchair tennis with other adaptive sportswomen. She shared that the adaptive sportswomen who serve as her mentors brought her out to play wheelchair tennis for the first time and connected her with another woman with a recent SCI. Julia expressed her gratitude for these connections, “it's pretty cool to just hang out with other female athletes that know what to do.”

Figure 33

Connecting with the Disability Community: Images G5 and J25

7.4.5.2. Navigating Social Interactions and Attitudes. The subtheme of *Navigating Social Interactions and Attitudes* refers to the images captured by participants that depict the challenges they faced in the community as they navigated others' attitudes and managed unequal social situations. Two participants—Angela and Gillian—shared a total of three images that represent this subtheme.

Angela captured an image that she called "my image at parties" (illustrated in Image A2), which reflects her viewpoint during social interactions with nondisabled individuals, showing the torsos and lower bodies of two people. She indicated that in situations like this, when individuals congregate and often stand around chatting, she has to determine how she fits in both socially and physically. Angela shared that she needs to learn how to adapt in situations where she is not the norm, and she frequently has to ask others to meet her where she is, requesting them “to sit down so that I can converse with their faces and not their crotches.” In another image, Angela illustrated how having a disability has influenced her social interactions within the community, as seen in Image A4, which depicts a farmers market she frequently visits. She said,

> Before I was injured, I was just one of those people in the crowd. But now I'm kind of identifiable, and a lot of the vendors know me, and I know them, some by name, and I know the ones who are very kind and understanding and will actually come around and hand me things rather than just, you know, try and reach across the counter.

Figure 34

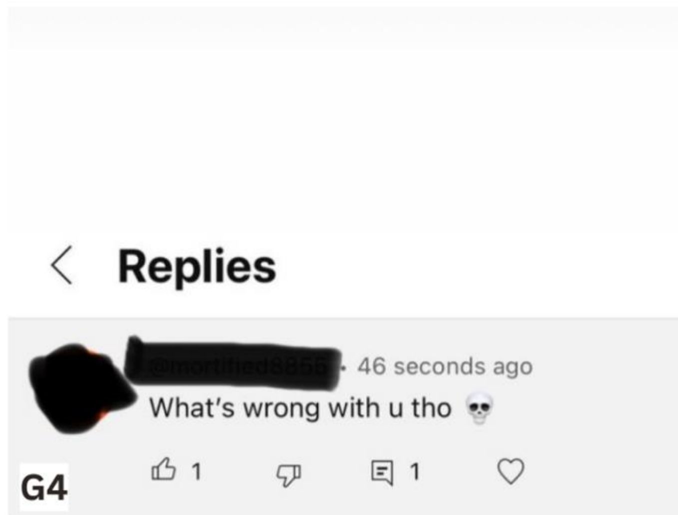
Navigating Social Interactions and Attitudes: Images A2 and A4

Angela explained that people's responses to her disability are shaped by their preconceptions of what she can do. However, once they get to know her, her patterns, and her needs, they come to see her as “a person that just happens to be moving around in a chair.” Captured in Image G4, Gillian illustrated the social interactions and attitudes regarding disability that she has to navigate online. Gillian shared one of her interactions with a nondisabled person on a dating app, describing it as "sort of typical” of her experiences on social media or in public. Image G4 shows a message she received in her direct messages on a dating app that says, "What's wrong with you though [skull emoji].” She said, “I think a lot of… able-bodied people expect people with disabilities to be like different or wrong or abnormal somehow, and that's why they ask kind of invasive questions like that.” Gillian expressed her frustration with these experiences, which she believed occurred only because she has a disability. She further stated

that she is often cautious about disclosing her disability to others, especially when dating, fearing rejection or making others uncomfortable. Gillian explained that this creates an “extra layer” she must navigate when contemplating potential relationships.

Figure 35

Navigating Social Interactions and Attitudes: Image G4



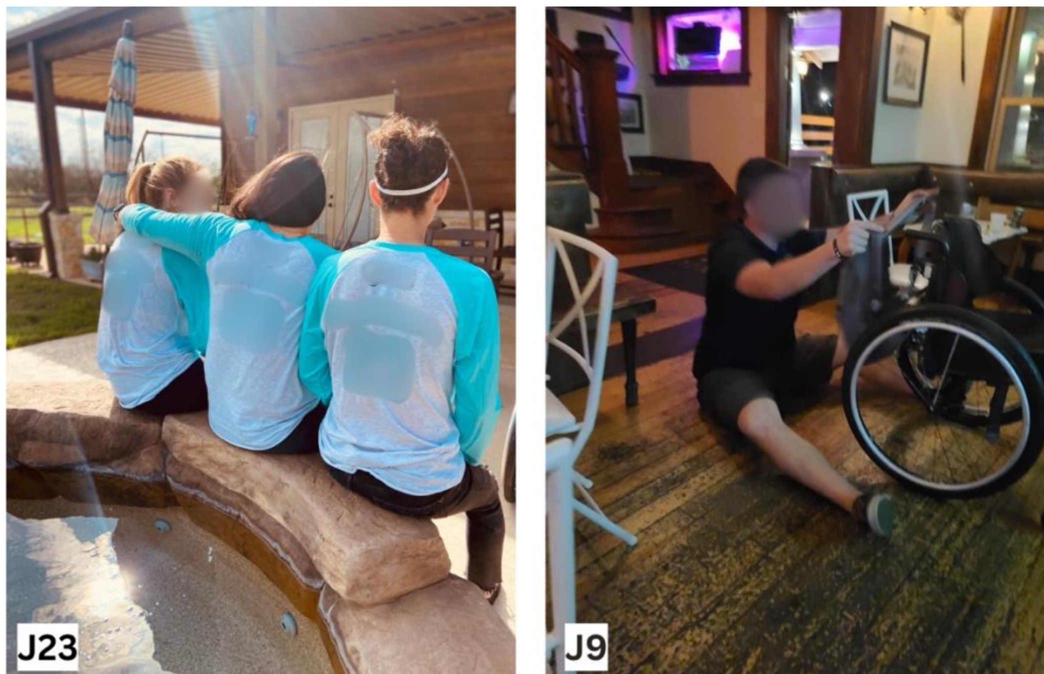
7.4.5.3. Social Support. The subtheme of *Social Support* refers to the images captured by participants that illustrate the support they have received, which has helped them engage with the community and feel comfortable interacting with others. Half of the participants—Angela, Chelsea, and Julia—shared a total of 13 images that represent this subtheme.

Julia captured her social support with Image J23, featuring her and her friends in shirts they created for her, which display her nickname and athletic number on the back, highlighting their support for her. She explained what the image meant to her: “So, I just felt welcomed and loved and supported. So, it just meant a lot to me because everyone's got my back, and I just

wouldn't be doing things if it wasn't for these two right here." Julia said her friends have helped her feel comfortable in all aspects of life. She commented on Image J9, which depicts her nondisabled friend playing with her wheelchair, that being with friends and having fun in public places has helped her feel as though she does not have to worry about having a disability, instead feeling welcomed wherever she goes.

Figure 36

Social Support: Images J23 and J9



In another image, Julia captured how her family has made her feel comfortable and encouraged her to try new things; this is reflected in Image J22, where she rides her Bowhead adaptive mountain bike with a group of motorcyclists. She explained that her uncle was among the bikers, and she enjoyed being included, "it was just nice to have them welcome me on my Bowhead, even though it's not, like, a motorcycle. I mean, all the wheels were welcome, and they wanted me to ride with them for the run." Another aspect of the social support that the

women received was the willingness of others to assist them and ensure they could continue to participate in meaningful routine activities. This is illustrated in Image A23, which shows Angela having her hair washed before a haircut, with her head reclined in the wash basin in an unconventional manner. She remarked, “This is meaningful because I was able to get my hair washed and cut, and the hairdresser that I've been with for quite some time is very willing to figure out how to make this work.”

Figure 37

Social Support: Images J22 and A23

7.4.6. Environmental Accessibility

The theme of *Environmental Accessibility* refers to the images captured by participants that demonstrate the environmental factors that have shaped their access to and participation in the community. It highlights the significance of accessibility and the conditions that impact it. All of the participants shared a total of 23 images that represent this theme. The *Environmental*

Accessibility theme is further divided into two subthemes: (a) *Accessibility Influences Access and Participation* and (b) *Does Accessible Mean Accessible*. What follows is a brief description of each with associated images.

7.4.6.1. Accessibility Influences Access and Participation. The subtheme of *Accessibility Influences Access and Participation* refers to the images captured by participants that reflect both the positive and negative experiences where environmental accessibility impacted their ability to participate in and navigate various aspects of their community. Five participants—Angela, Chelsea, Julia, Kendall, and Miranda—shared a total of 21 images that represent this subtheme.

Angela captured Image A19, which shows the front door of her house featuring a keypad and a built-in rope that enable her to enter and exit independently. She mentioned that these home adaptations "provides me a level of freedom and independence that I didn't have previous to it." The women highlighted a number of positive experiences of modifications that helped expand their freedom of movement. Julia shared Image J18, which depicts her maneuvering her wheelchair along an accessible path across the beach's sand. She emphasized that "being able to go to the water easily and not having to be carried or rolled through the sand, it just makes it so much easier." Julia advocated that built paths like the one pictured are "what all the beaches need. Cause all, most beaches don't have accessible, umm, wheelchair-accessible walkways," indicating that this was an infrequent experience of accessibility.

Figure 38

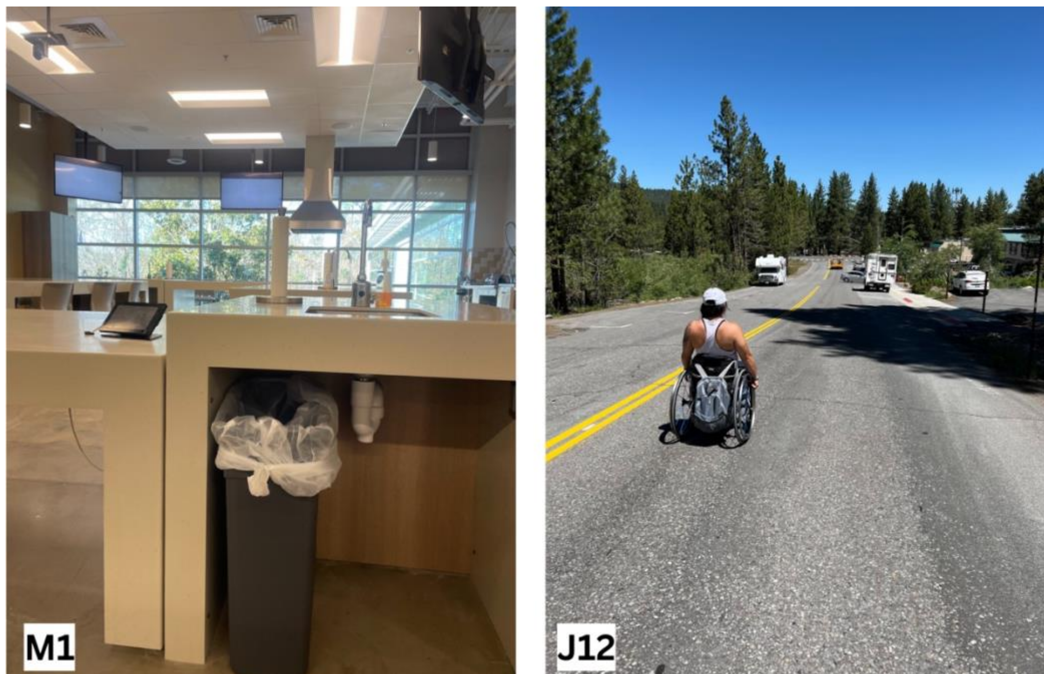
Accessibility Influences Access and Participation: Images A19 and J18

Similarly, Miranda captured Image M1 of a fully accessible teaching kitchen with a raised countertop for wheelchair users. Miranda said, “Being a registered dietitian and someone with a disability, I know the importance of, like, food preparation and access to resources to allow you to prepare food as independently as possible.” She emphasized that this is an atypical kitchen design, yet it is aspirational for her as she aims to work hard and save enough money to create a more accessible kitchen that she can use. The women also documented several negative experiences where accessibility affected access and participation. Julia demonstrated her need to adapt to environmental barriers that affected her ability to navigate the community, as shown in Image J12, which depicts Julia pushing her wheelchair down the inside of a street lane with cars driving ahead of her. She explained,

Being in the middle of the road, it's just more flat. Otherwise, I'd be on the sidewalk, but most of the time, the sidewalk is blocked or just not accessible, and too many bumps. And then I get to a really big curb. And I'm like, how am I supposed to get up or down this? And just a lot of obstacles sometimes, so I just. I'm used to just going... if there's no traffic and I know my area, I just go to the road, and I roll down because why not?

Figure 39

Accessibility Influences Access and Participation: Images M1 and J12

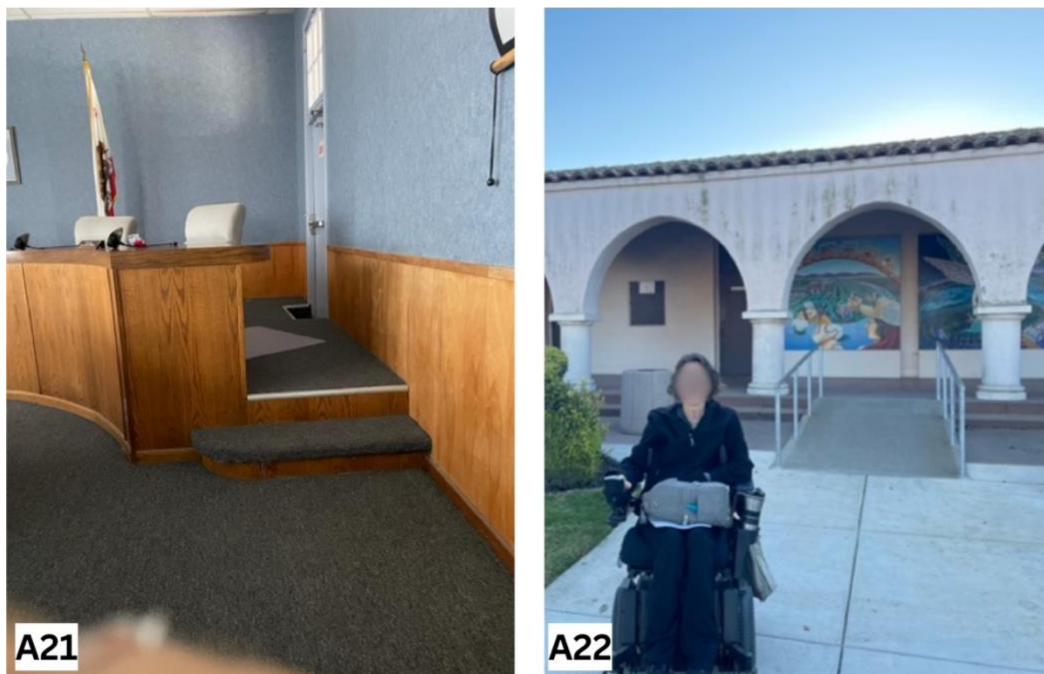


Julia said that a common issue is that the sidewalks are blocked or in poor condition, which makes travel difficult. Because inaccessibility often impacts her rolling experience, she has had to adapt by making risky decisions to navigate her wheelchair on roads meant for motor vehicles. Angela pointed out a barrier in her community that prevented her from accessing the only light switch in the room, as shown in Image A21, which depicts a pair of steps separating her from the seating area for city council members. She said this “highlights that

despite all of the advances that have been made in making the world, umm, functional, there are still aspects that exist that just aren't." When discussing Image A22, which represents a ramp with handrails leading up to the outside of the same building pictured in Image A21, Angela hypothesized that the architects had to choose one accessible building design or the other due to the community being less affluent.

Figure 40

Accessibility Influences Access and Participation: Images A21 and A22



7.4.6.2. Does Accessible Mean Accessible. The subtheme of *Does Accessible Mean Accessible* refers to the images captured by participants that demonstrate that all accessibility is not equal. Just because a space is designated to be accessible with a wheelchair user marking does not mean a wheelchair user can access that space to participate in the community. Half of the participants—Gillian, Julia, and Kendall—shared a total of three images that represent this subtheme.

Gillian expressed her frustrations while commenting on Image G6, which shows a vehicle parked in an accessible parking space. She explained that the situation in which a nondisabled person parked in an accessible parking space occurs “not infrequently." She expanded on the blocking of accessible spaces,

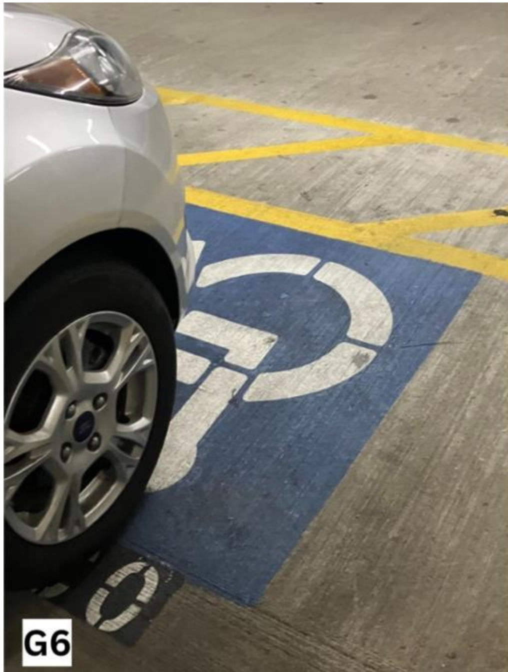
> So, like, needing a handicapped parking spot, but then at the same time, like, other people will block your access to it. So even though you could potentially access the environment, there are still barriers… that get in your way.

Gillian said that her frustrations in these experiences are “usually at other people,” but sometimes she will “get really down, I'll start to spiral and be like, well, if I wasn't disabled, then I wasn't in a chair, et cetera, et cetera, my life would be so much easier.” While commenting on Image K7, Kendall shared how these experiences have influenced her thinking as she navigates the community,

> It's just something I have to think about every time I'm going to do errands. I have to make sure that, you know, if there isn't a disabled parking spot, that I find a spot on the end of a row of cars so that I have space for my wheelchair and door to open.

Figure 41

Does Accessible Mean Accessible?: Images G6 and K7



The need for vigilance due to the uncertainty of environmental accessibility, as Kendall states, “so that I can have access and not get boxed in and stuck,” indicates that community participation is not guaranteed for people with disabilities despite the existing legislative mandates. Sometimes, even the seemingly accessible accommodations are not truly accessible in practice, as suggested by Image J20, which shows a hotel roll-in shower equipped with a bench, grab bars, and a handheld showerhead. Julia observed that she sees “a shower that's not really accessible for me” in Image J20 because “the bench is, like, further, and I couldn't reach the knob, and it doesn't make sense to me sometimes.” She emphasized that “something that needs to be worked on is just, it's wheelchair accessibility, like, labeling it like that and making sure it is actually wheelchair accessible.” The women’s images underscore the limits of accessibility and how this impacts their ability to navigate their community.

Figure 42

Does Accessible Mean Accessible?: Image J20

7.4.7. Feeling Like a Disabled Person

The theme of *Feeling Like a Disabled Person* refers to the images captured by participants that illustrate the factors influencing their sense of identity as disabled individuals while navigating the community. All of the participants shared a total of 19 images that represent this theme. The *Feeling Like a Disabled Person* theme is divided into three subthemes: (a) *Having to Adapt and Use Adaptations*, (b) *Encountering Inaccessible Spaces*, and (c) *Salience of Disability*. What follows is a brief description of each, along with associated images.

7.4.7.1. Having to Adapt and Use Adaptations. The subtheme of *Having to Adapt and Use Adaptations* refers to the images captured by participants that illustrate how, when they recognized the need to adapt or use adaptations to access or engage with the community, they

experienced a heightened awareness of themselves as disabled individuals. This stems from their association of disabled people with the necessity of using adaptations in their daily lives. Half of the participants—Angela, Julia, and Kendall—shared a total of nine images that represent this subtheme.

Image J1, captured by Julia, depicts her using adaptive controls from the driver's seat of her truck. Due to her inability to use her legs, Julia invested in an expensive vehicle conversion and adaptive driving equipment that enabled her to travel independently within her community. Aware that many disabled individuals must obtain similar adaptive technologies to deal with these challenges, she sees herself as a disabled person in these circumstances. In a similar situation, Kendall captured Image K8, which depicts her holding a makeshift tree branch aloft to reach and press a light switch that is separated from her by furniture. She commented on the image, stating,

> I feel disabled because I can't just stand up and reach over and turn on the light like most people can so. There's a tool that has to be used to bridge that gap. And then and that type of scenario is what feels like a really fundamental part of being disabled, is sort of constantly needing to come up with workarounds or tools or adaptive systems to deal with a whole host and variety of situations.

Figure 43

Having to Adapt and Use Adaptations: Images J1 and K8

The women acknowledged that using adaptive tools and adapting to their impairments is a shared experience among individuals with disabilities. They observed that these circumstances increased their awareness of their bond with others with disabilities. Angela illustrated this thinking with Image A1, representing a sliced hamburger on a plate with silverware resting on a table placemat. She said that this situation made her perceive herself as a disabled person because “I look at the burger and I think, OK, how my, I really want to eat this hamburger. How am I going to? How am I going to pull this off?” This recurring experience during meals that challenge her limited hand function makes her aware of her disability and leads her to recognize herself as a person with a disability. In Image J18, Julia illustrated her experience using a hard path to navigate the sand of the beach. She believed this path was specifically intended for wheelchair users like herself, which prompted her to reflect on her

identity and led her to perceive herself as a disabled person. Julia's experience highlighted the identity implications of using infrastructure designed for accessibility.

Figure 44

Having to Adapt and Use Adaptations: Images A1 and J18

7.4.7.2. Encountering Inaccessible Spaces. The subtheme of *Encountering Inaccessible Spaces* refers to the images captured by participants that show how, when they faced inaccessible spaces in the community, they experienced a heightened awareness of themselves as individuals with disabilities. These encounters served as reminders of their bodies, capabilities, and limitations. Four participants—Angela, Chelsea, Gillian, and Miranda—shared a total of four images that represent this subtheme.

Gillian demonstrated that parking spaces made inaccessible by individuals without a disability parking placard or license plate, even those marked as accessible with a wheelchair

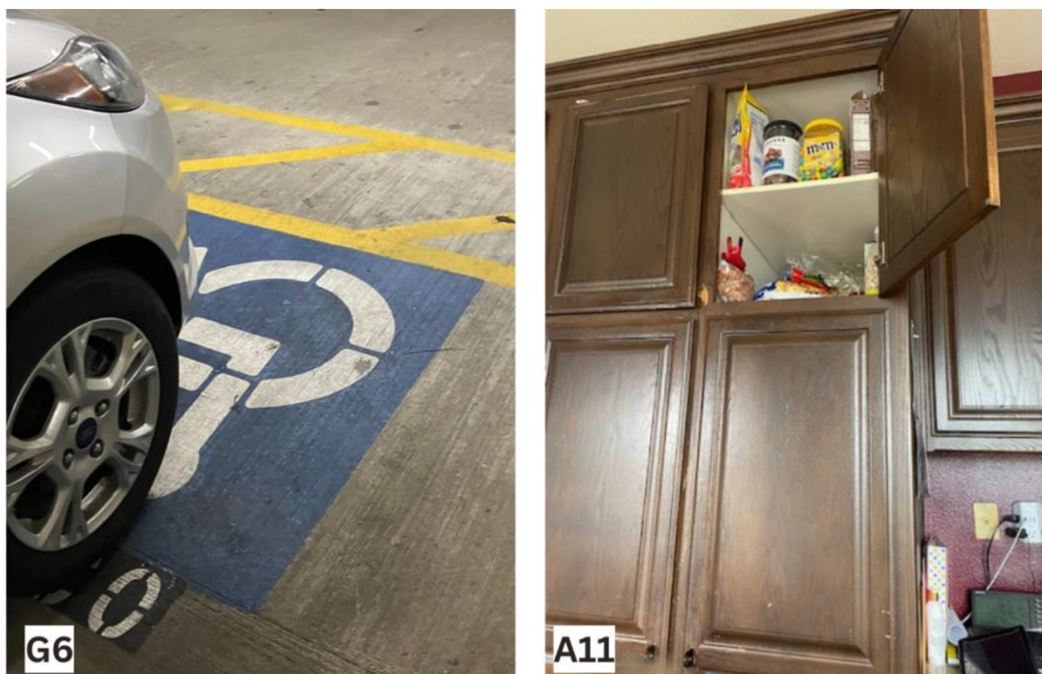
symbol (as shown in Image G6 depicting a vehicle parked in an accessible parking spot), serve as a frustrating reminder to her of her disability. She explained,

> It makes me feel disabled when I can't access things because, to me, it just sort of like slaps you in the face like ohh. Like, literally, this is what being disabled means is, like, not being able to do stuff or access stuff. And so, it's just a really clear reminder of what that means.

Angela captured Image A11, which shows her encounter with a cabinet in her home filled with food but out of her reach. She explained that in moments like these, when she wants to access something beyond her reach, and no one is around to help her, she recognizes, "I am living in a world that is designed for people without disabilities." This recognition triggered an awareness that she is one of the people the world is not designed for.

Figure 45

Encountering Inaccessible Spaces: Images G6 and A11



Similarly, Miranda explained she felt like a disabled person when she could not see herself in a hotel bathroom mirror that was placed too high on a bathroom wall for her to view (this is depicted in Image M4). She said that such a simple thing was representative of "the little day-to-day frustrations" that she has to deal with that serve as a reminder of what she is – a person with a disability. In Image C5, which shows a pair of doors without an access button, Chelsea shared how encountering inaccessible environmental structures makes her feel like a disabled person because, as she expressed, only those with disabilities notice the access problems: "You only really realize that if you're struggling, like with a disability or something."

Figure 46

Encountering Inaccessible Spaces: Images M4 and C5

7.4.7.3. Salience of Disability. The subtheme of *Salience of Disability* refers to the images captured by participants that illustrate how the visibility of disability in everyday situations heightens their awareness of how they present themselves in community spaces and

how they appear different or disabled compared to others. Four participants—Angela, Gillian, Julia, and Kendall—shared a total of seven images that represent this subtheme.

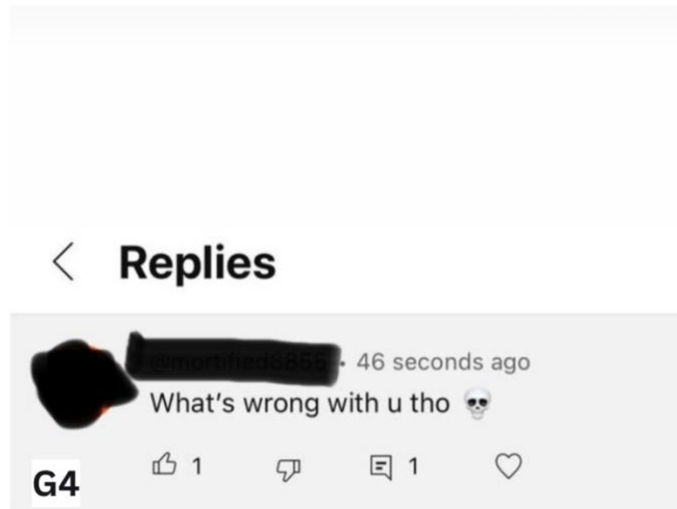
Kendall captured an example of this theme with Image K9, which shows her leaving the supermarket and crossing the street to the parking lot with groceries on her lap as she drops a bottle of laundry soap. She explained that being seen visibly struggling in a public space emphasized her disability:

> And then if I fail and something goes boom, you know, a lot of the time somebody will come running over. Oh, can I help you? Can I help you? And I guess that's part of what makes me feel disabled is suddenly, like, it'd be one thing if I was in a vacuum, and nobody saw or knew or heard that I was carrying stuff on my lap, and I dropped something. No big deal. Pick it up. Keep going, but it's somehow the public interface, you know, it's like when people see that, and they rush to your help. Then, suddenly, I feel my disability. So, it's like the comparison to how they are that makes me feel disabled.

Gillian identified an example of when her disability becomes salient, specifically when others call attention to her impairment and ask intrusive questions. This is illustrated in Image G4, which shows a message she received on a dating app stating, “What's wrong with you though [skull emoji].” She explained that this is a typical interaction she experiences both online and in person, where people bluntly ask intrusive questions. It makes her “feel disabled” because it serves as a reminder of another challenge she must face due to her disability.

Figure 47

Salience of Disability: Images K9 and G4



When Julia is with friends or family who make her feel at ease, she mentioned that she might not feel as much like a disabled person, allowing her to momentarily forget about having a disability. This is reflected in Image J6, which shows her shooting a shotgun at an aerial target with a friend supporting her chair. She explained that having friends who support and encourage her to engage in activities with them—friends who “don't see my disability”—helps her not see herself as disabled either.

Figure 48

Salience of Disability: Image J6

7.4.8. Gratitude.

The theme of *Gratitude* refers to the images captured by participants that demonstrate the various things they are appreciative of and how these things positively shape their lives with a disability. Two participants—Angela and Julia—shared a total of 13 images that represent this theme.

The women shared several images that they used to express their gratitude for being able to navigate the community independently. Angela commented on Image A18, representing her husband riding away on his bicycle, saying,

> This one is meaningful in that we are both heading off to activities independently that we both enjoy, and I like the fact that I can head off and do something by myself without necessarily needing somebody with me, and he can head off and continue to do

activities that he enjoys without for that time period worrying about me or having to take care of me.

Angela appreciated her ability to navigate her community and engage in activities on her own. She also captured Images A9 and A10 of city buses, one featuring an extended accessible ramp. Angela explained that these images represent independence and freedom. She noted that the existence and availability of these services “enable me to exist in the community, to be able to maneuver around the community in an effective way.” Angela also expressed her gratitude for the bus drivers, sharing her amazement at their commitment to their work and the kindness they show to others like her. She noted that she would not have encountered or witnessed this before her disability, indicating that her life with disability has fostered positive and meaningful relationships and experiences.

Figure 49

Gratitude: Image A18 and A9

The women shared images that they used to express their gratitude for those who assisted them and helped create joy. Angela commented on Image A25, depicting a slice of avocado toast that has been thoughtfully prepared, saying, “It shows me that there are thoughtful people out there who are willing to take my needs in stride and to actually make something beautiful of it.” She explained that the restaurant employees do this for her every week, turning her request for assistance into “a thing of beauty,” which makes her smile.

Figure 50

Gratitude: Images A10 and A25

7.5. Discussion

The aim of this study was to use a Photovoice approach to provide women athletes who have acquired a SCI a visual voice to capture the elements that shape their everyday life experience of (a) *having a disability*, (b) *being disabled*, and (c) *living with disability*. Photovoice data analyses revealed eight overarching themes: (a) *Taking Care of the Disabled Body*, (b)

Continuity and Attachment, (c) *The Disability Tax*, (d) *Adaptations*, (e) *Interpersonal Connections*, (f) *Environmental Accessibility*, (g) *Feeling Like a Disabled Person*, and (h) *Gratitude*. What follows is a discussion of what these themes tell us about (a) being a woman athlete with a disability after SCI and (b) the meaning of *having a disability*, *being disabled*, and *living with disability*.

7.5.1. Woman Athlete After SCI

The themes constructed from the captured images demonstrated how the women came to participate in adaptive sport and maintain their relationship with sport. Several women shared a desire to reclaim parts of their athletic lives prior to SCI. Those who were able to do so through adaptive sport discussed the benefits, including regaining the thrill of competition, maintaining their physical strength, and fostering a peer network. The women involved in adaptive sport and physical activity emphasized their gratitude for their relationships with other women athletes with disabilities. They shared how these relationships supported them by creating an atmosphere that encouraged women with disabilities to be active, developing relationships with other women athletes with disabilities, and introducing them to novel adaptive sport interests.

Aside from adaptive sport-related experiences, the women generally had difficulty speaking about their gendered experiences as athletes after SCI. Several of the women, when discussing an image that they assigned to the theme of 'What it means to be a woman athlete after spinal cord injury', focused on their athletic experience in a way that was genderless; their responses centered more on the utility and performance of sport. The women's images captured only a few insights into the intersection between being a woman, an athlete, and

disabled. The participants found it challenging to capture representations of this experience, as Miranda explains:

> It was kind of hard for me to think of something for that, just because I'm just like another person. So, it's hard for me to say, like, oh, this is a specific instance of, like, what it means to be a woman with a disability.

While the women highlighted various aspects of their experiences as women athletes with disabilities, there were few commonalities among the discussed experiences that allowed for the construction of a theme or subtheme. Angela and Miranda's images captured their interactions and relationships with nondisabled individuals who assisted them in completing activities they perceived as typically associated with women, such as getting their hair cut at the salon or putting their hair up into a ponytail. And Gillian and Kendall's images captured how having a disability was viewed as a "discrediting attribute" (Goffman, 1963) that they felt inclined to hide when navigating online dating and searching for suitable clothing for their disabled body.

7.5.2. Having a Disability

In this study, *having a disability* was conceptualized as the meaning assigned to possessing an impaired body as one navigates the world. Based on the themes constructed from the captured images, *having a disability* means (a) being different from the norm and (b) having to pay the invisible disability tax. Additionally, *having a disability* was characterized as being (a) social-relational and (b) contextual in nature.

The themes constructed from the women's captured images emphasized that *having a disability* means being different from the norm, i.e., nondisabled individuals capable of

“normal” physical functioning. Throughout the themes, the women expressed perceptions of being viewed as different, wrong, or abnormal. These perceptions align with Western societal attitudes rooted in a medical model of disability and its biophysical assumptions of normality (Smith & Bundon, 2018), which perpetuate a normal/abnormal binary where disabled individuals are perceived as defective. The themes illustrate how these attitudes were prevalent in the women’s interactions with nondisabled individuals. Such attitudes—that *having a disability* equates to being personally flawed or deviating from the norm—are prominently reflected in the *Interpersonal Connections* theme, particularly when Gillian demonstrates encountering intrusive questions from nondisabled individuals suggesting she was flawed in some way. The themes also illustrated how women perceived *having a disability* set them apart from the norm. Several of the themes, particularly *Adaptations*, discussed the women’s reliance on mobility aids and adaptive sports equipment, the necessity of creating workarounds, and their efforts to adapt to various activities and environments to participate in or gain access—tasks that they recognized nondisabled individuals typically do not have to undertake. The *Shedding the Wheelchair* subtheme showed how these perceptions posed challenges for re-embodiment, most notably demonstrated by Julia when she expressed her dislike for using a wheelchair and her feelings of being constrained due to societal attitudes regarding how she should behave as a wheelchair user. These findings contradict existing research, which suggests that wheelchair users living independently view wheelchair use as liberating (Papadimitriou, 2008; Sapey et al., 2005).

The themes constructed from the captured images demonstrate that *having a disability* means having to pay the invisible disability tax. Specifically, *The Disability Tax* theme illustrated

the women's experiences with having to pay the additional labor and financial costs needed to manage interactions with the social environment simply for *having a disability*. This finding aligns with contemporary literature (Emens, 2021; Olsen et al., 2022), highlighting the burdensome, extra, and uncompensated labor and financial costs that people with disabilities must pay on a daily basis to mitigate the effects of disablism in their relationships with the social environment. The themes of *The Disability Tax* and *Interpersonal Connections* showed the women's experiences in navigating the disability tax, including (a) the emotional labor of navigating stigma and advocating for themselves in social interactions, (b) the intellectual labor of finding workarounds to overcome environmental accessibility challenges, (c) the technological labor involved in using and maintaining assistive technologies, and (d) the financial costs to obtain assistive devices. In contrast to the social-relational model of disability (SRM; Thomas, 1999, 2007), these themes also emphasize how the women exercised autonomous rather than passive agency through their labor and financial expenditures to overcome social oppression stemming from avoidable restrictions encountered in interactions with the social environment. Additionally, the themes indicate that the conditions influencing experiences of *having a disability* can do more than undermine a disabled individual's psychological and emotional well-being, as shown in the SRM (Thomas, 1999, 2007); they can also affect one's social and financial well-being, reflecting a more holistic understanding of the experience of *having a disability*.

When discussing their images, regardless of the themes, the women shared how the disability tax (e.g., the added labor and financial costs associated with *having a disability*) was often invisible to most nondisabled individuals. The theme *The Disability Tax* further showed

how the women felt disadvantaged due to the inability to engage in the community on an equal and fair basis. This was because their efforts to maintain their autonomy and participate in a world frequently designed for those without disabilities often went unnoticed and unrecognized by nondisabled individuals. This aligns with current literature that indicates the disability tax frequently remains invisible to nondisabled people and is largely absent from public discourse (Emens, 2021). These findings support contemporary literature (Scully, 2010) that suggests the invisible labor and costs paid by disabled individuals are a result of disablism in social interactions between nondisabled and disabled people.

The themes constructed from the images illustrated that *having a disability* is social-relational in nature, consistent with the SRM (Thomas, 1999, 2007). The themes *Environmental Accessibility* and *Interpersonal Connections* depicted the women's relationships with their social environment and how these conditions produced disablism, influencing their experiences of *having a disability*. Disablism is "the social imposition of avoidable restrictions on the life activities, aspirations, and psycho-emotional well-being of people categorized as 'impaired' by those deemed 'normal'" (Thomas, 2012, p. 211). The themes in this study reflected the women's encounters with social restrictions due to (a) disabling social barriers (e.g., inaccessible doors, steps, and cabinets), (b) negative interactions with cultural constructions of disability (e.g., facing negative societal attitudes both online and in-person), and (c) frustrations stemming from structural disablism (e.g., issues with inaccessible parking spaces). These experiences align with many of the social contexts proposed by the SRM (Thomas, 1999, 2007) in which disablism can emerge. In contrast to the SRM, however, several themes, including *Taking Care of the Disabled Body*, *Adaptations*, and *Interpersonal Connections*, illustrated how

women exercised social agency autonomously rather than passively in their interactions with the social environment. An autonomous agent is "both self-determining—that is, she can decide in some meaningful way how she wants her life to go; and also effective, which means she can make what she has autonomously decided she wants to have happen, happen" (Scully, 2010). The themes demonstrated the women's capacity to act independently and make their own choices on how to achieve their goals (e.g., altering clothing to celebrate the body, advocating for themselves in social interactions, modifying exercise equipment for their athletic pursuits), even within the constraints of social structures and norms that portray disability as a personal flaw to be hidden.

The themes constructed from the images also illustrated how *having a disability* is contextual in nature. This is supported by contemporary literature (Thomas, 1999; Tøssebro, 2004; WHO, 2001), which suggests that what constitutes disability can vary across different times, places, and groups of people. The theme of *Environmental Accessibility* showed how interference with accessible spaces can lead to structural disablism at any time. In the *Interpersonal Connections* theme, it was demonstrated how social relations with nondisabled individuals can create or alleviate social constraints, depending on the women's familiarity with these individuals, the willingness of nondisabled people to collaborate in reducing social barriers, and their preconceptions of disability. Additionally, the theme of *Adaptations* highlighted how access to and the use of personal mobility devices and adaptive sport equipment can influence the disabling nature of certain environments, enhancing the women's independence and opportunities. Finally, the theme of *Environmental Accessibility* captured images of adaptive structures that transformed traditionally inaccessible spaces, such as

beaches or kitchens, into truly accessible environments. These themes, understood together, illustrated how the experience of *having a disability* can change depending on various contexts.

In summary, the results from this study suggest that *having a disability* means (a) being different from the norm and (b) having to pay the invisible disability tax. Additionally, *having a disability* was characterized as being (a) social-relational and (b) contextual in nature. These results are consistent with Western societal norms rooted in a medical model understanding of disability (Smith & Bundon, 2018). Furthermore, they align with contemporary literature indicating *having a disability* is social-relational (Thomas, 1999; Tøssebro, 2004) and context-dependent (Oliver, 1990; Thomas, 1999; Tøssebro, 2004; WHO, 2001). These findings extend the current literature by illustrating the autonomous agency exercised by women athletes with disabilities in relation to conditions that produce disablism in the social environment.

7.5.3. Being Disabled

In this study, *being disabled* was conceptualized as the meaning assigned to a disability identity and the effect it has on relationships with oneself, others, and the surrounding environment. Based on the themes constructed from the captured images, *being disabled* is characterized as multidimensional in nature. Additionally, the meaning of *being disabled* is shaped by (a) situation and context, and (b) comparison(s) with other people.

The themes constructed from the images demonstrate that *being disabled* is multidimensional in nature. This aligns with contemporary literature (Gill, 1997; Putnam, 2005; Caldwell, 2011; Dunn & Burcaw, 2013; Forber-Pratt & Zape, 2017) that suggests disability identity has both internal and external dimensions, as it is commonly conceptualized as both personal and intrinsic to the individual, as well as communal and shared. The theme *Feeling*

Like a Disabled Person showed that the women associated *being disabled* with two main characteristics: (a) the frequent reliance on adaptations, workarounds, and assistive technologies to navigate challenges associated with *living with disability* and (b) the inability to do or access things due to *having a disability* in an inaccessible environment. These results highlight how the physical reality of *having a disability*, interactions with the social environment, and adaptations made while *living with disability* contribute to *being disabled*. Moreover, the *Feeling Like a Disabled Person* theme showed that the women's perceptions of *being disabled* were based on what they believed to be shared experiences of people with disabilities. This is consistent with the current literature (Gill, 1997; Putnam, 2005; Caldwell, 2011; Dunn & Burcaw, 2013; Forber-Pratt & Zape, 2017), which indicates *that being disabled* is shaped by shared experiences and cultural understandings of the disability minority group.

The themes constructed from the images also illustrated that *being disabled* is shaped by situation and context. The theme *Feeling Like a Disabled Person* demonstrated that the women experienced a heightened or diminished awareness of their disability identity in situations where circumstances arose that made *having a disability* more or less salient. This aligns with research indicating that among an individual's many intertwined identities (Sheuringer, 2016), some become more prominent than others depending on the situation (Stryker & Serpe, 1982, 1994) and context (Dunn & Burcaw, 2013). Additionally, these findings are consistent with contemporary literature (Miller & Garran, 2017) that supports the idea that an individual's awareness of their social identities fluctuates depending on social context. In the *Feeling Like a Disabled Person* theme, it was shown that the women felt more or less like a disabled person depending on the salience of their disability in various situations. The situations

in which they reported feeling more like a disabled person included (a) relying on adaptations or assistive technologies to gain access, (b) navigating challenges due to the limitations of having a disabled body, (c) encountering inaccessible environments (e.g., raised bathroom mirrors and kitchen cabinets) or barriers to accommodations within the community, and (d) nondisabled individuals making unwelcome comments drawing attention to their disabled body and how it deviates from societal norms. The situations in which the women reported feeling less like a disabled person were when nondisabled people facilitated situations where the women felt comfortable and *having a disability* was not at the front of their minds. These findings support previous research (Moffat & Miehls, 1999), which indicates that how social identity is constructed varies from interaction to interaction, as the identity that emerges with one person may differ from the identity that emerges with another. Additionally, these findings align with research indicating that social identity is relational and situational (Eriksen, 2001), as it is shaped through interactions within the social environment (Gee, 2001; Mead, 1934).

The themes constructed from the images also illustrated that *being disabled* is shaped by comparison with other people. Specifically, the theme *Feeling Like a Disabled Person* showed that when the women perceived their experiences *living with a disability* or *having a disability* as noticeably different from nondisabled people in a given situation, they often became more aware of their disability identity. This aligns with contemporary literature (Gill, 1997; Putnam, 2005; Caldwell, 2011; Dunn & Burcaw, 2013; Forber-Pratt & Zape, 2017) that suggests that disability identity develops in relation to others. The theme *Feeling Like a Disabled Person* illustrated how awareness of *being disabled* was heightened when nondisabled individuals were present, particularly in public, as their mere presence acted as a benchmark for

comparison. Kendall, in particular, felt more conscious of *being disabled* when she struggled with tasks alongside nondisabled people.

In summary, the results of this study suggest that *being disabled* is multidimensional in nature. Furthermore, the results indicate that the meaning of *being disabled* is shaped by (a) situation and context and (b) comparison with others. These findings show that the physical reality of *having a disability*, interactions with the social environment, and adaptations made while *living with disability* can heighten awareness of *being disabled*, particularly in relation to others. This aligns with previous research indicating that certain identities become more salient depending on the situation (Stryker & Serpe, 1982, 1994) and context (Dunn & Burcaw, 2013). Additionally, these findings reinforce the idea that social identity is relational and situational (Eriksen, 2001), shaped by interactions within the social environment (Gee, 2001; Mead, 1934).

7.5.4. Living with Disability

In this study, *living with disability* was conceptualized as the meaning assigned to the process of adapting to disability and the factors that affect this process. Based on the themes constructed from the captured images, *living with disability* is a multidimensional process, and the key factors found to affect that process are (a) a desire and attempts to reclaim the past and (b) access uncertainty.

The themes constructed from the images demonstrate that *living with disability* is a multidimensional process consistent with contemporary literature (Bishop, 2005; Devins & Shnek, 2000; Kendall & Buys, 1998; Livneh, 1986, 2001). The themes showed that the process of *living with disability* involves the interaction of internal and external contextual factors, as was similarly demonstrated in *having a disability* and *being disabled*. Specifically, the themes

Taking Care of the Disabled Body and *Adaptations* illustrated how internal factors, such as the women's personal coping strategies (e.g., caring for the disabled body, using adaptive equipment, seeking assistance from others, and adaptive thinking), influenced their adaptation to both *having a disability* and various disabling external factors. The themes *Interpersonal Connections*, *Environmental Accessibility*, and *Adaptations* illustrated how external factors, such as their relationships and interactions with the social environment (e.g., connections with both disabled and nondisabled people, and encounters with environmental accessibility), impacted independence, influenced community participation, and created conditions that influenced *having a disability* and *being disabled*.

The themes also illustrated a key factor that influences the experience of *living with disability*: a desire and attempts to reclaim the past. The theme *Continuity and Attachment*, in particular, demonstrated their efforts to regain aspects of their lives prior to SCI, particularly those associated with an athletic sense of self. This theme illustrated that the women engaged in a variety of adaptive athletic activities by modifying previous activities, acquiring adaptive equipment, and adjusting how they participated. These adaptations facilitated the reclamation of an athletic identity and allowed continued involvement in meaningful activities, albeit in nontraditional ways. These findings align with existing research (Richardson et al., 2017), which has shown that the previous identities of women with disabilities have facilitated re-engagement in activities they pursued prior to their injury as a means of reclaiming a sense of self. While the adaptive sport experiences shared in the theme *Continuity and Attachment* were matter-of-factly discussed as an avenue to continue being an athlete after SCI, they also provided satisfaction and fostered positive relationships with other women athletes with

disabilities, which in turn helped them learn how to adapt to disability. Existing research (Zike et al., 2024) has demonstrated that adaptive sport participation fosters a sustained relationship with sport and facilitates the re-establishment of an athletic identity among athletes with SCI. It can also serve as a source of satisfaction and fulfillment (Goraczko et al., 2021) and make it easier to adjust (Goraczko et al., 2020).

Another key factor that the themes in this study demonstrated affected the process of *living with disability* is access uncertainty. The themes *Environmental Accessibility* and *Adaptations* showed that access is not guaranteed, which is consistent with existing research (Stüssi, 2022) that shows the existence of temporary barriers can have enduring impacts on accessibility for disabled people. The theme *Environmental Accessibility*, in particular, showed community structures that, despite legal requirements for accessibility, remained inaccessible for various reasons. This theme illustrates that just because a space or structure is designated or legally mandated to be accessible, it does not guarantee that wheelchair users can actually access it or utilize the accommodation to participate in the community. It was also demonstrated in the theme *Environmental Accessibility* that access to these spaces was constrained by nondisabled people occupying them, the limited number of available spaces, and accommodations, such as a roll-in shower, not being accessible in practice. The theme *Adaptations* showed how the women dealt with access uncertainty in *living with disability*; they expressed the need to be vigilant in planning for and navigating their community due to the uncertainty of their environment. This theme illustrated the various ways the women created a safety net of resources and contingencies to ensure their autonomy in addressing their needs and participating in the community. It also illustrated that this vigilance took its toll as the

constant planning made the women feel as though their lives lacked spontaneity. This finding aligns with contemporary literature (Bishop, 2005a, b; Devins & Shnek, 2000; Kendall & Buys, 1998; Livneh, 1986, 2001) that highlights the interplay between the individual and the environment in *living with disability*.

In summary, the results from this study suggest that *living with disability* is a multidimensional process, and two key factors that affect the process include (a) a desire and attempts to reclaim the past and (b) access uncertainty. The findings align with contemporary literature (Bishop, 2005a, b; Devins & Shnek, 2000; Livneh, 2001), which suggests *that living with disability* is a complex process involving interacting internal and external contextual factors.

7.5.5. Limitations

This study is foundational research, providing important insights into key constructs that may inform future investigations (ED & NSF, 2013). Consistent with the inherent methodological constraints of foundational research, this study's limitations include the specificity of the sample and the substantial time and effort required of participants due to the chosen methodology. Both factors contribute to challenges in developing practical implications. The Photovoice approach (Wang & Burris, 1997) produced important findings rooted in the specific context of the community—women athletes with acquired SCI—due to its participatory nature. Due to the context-specificity of the sample, the study's findings cannot be directly applied to other populations. To determine if the findings of this study are transferable to other subpopulations of individuals with acquired disabilities, including those with various physical disabilities, non-athletes, and different genders, it is essential to explore the constructs of

having a disability, *being disabled*, and *living with disability* and their relationships with samples of those subpopulations (ED & NSF, 2013). Additionally, while employing the Photovoice approach (Wang & Burris, 1997) as a methodology can empower participants to decide the content and manner in which they convey their thoughts and emotions (Asaba et al., 2014), its use may have imposed considerable demands on the women in this study. Photovoice necessitates a more substantial investment of time and effort from participants compared to what is typically expected in traditional qualitative single-interview studies (Sutton-Brown, 2014). Consequently, the women may have opted to fulfill only the minimum requirements of study tasks or may have chosen to withdraw from participation entirely. This study was not exempt from the consequences of these challenges. Although the women submitted a diverse array of captured images, some contributed only the minimum number of images stipulated by this study's photographic guidelines. This resulted in noticeable differences in the total number of images collected across participants. Due to these limitations, it is prudent to exercise caution when applying the findings to diverse populations or formulating practice recommendations.

7.5.6. Future Research

Despite the limitations of foundational research, this study has produced knowledge that extends the existing literature and serves as a basis for future studies aimed at advancing science and clinical practice related to psychosocial adaptation to acquired disability following SCI. The next steps in research on psychosocial adaptation to acquired disability after SCI should involve conducting early-stage and exploratory research on the relationships between the constructs of *having a disability*, *being disabled*, and *living with disability* (ED & NSF, 2013). Such

research advances knowledge by exploring relationships between constructs and establishing potential conceptual and theoretical connections between constructs and outcomes. The findings of this study emphasize that *having a disability*, *being disabled*, and *living with disability* are relational and contextual in nature. Future research is encouraged to investigate ***how*** the relationships between these constructs are shaped by social contexts and what outcomes are associated with various social contextual factors. This early-stage and exploratory research can generate valuable insights into the connections between *having a disability*, *being disabled*, and *living with disability*, as well as the effects of these relationships on psychosocial adaptation outcomes.

One of the most prominent findings from this study extends the existing literature by illustrating how women athletes with disabilities demonstrate autonomous agency in their experiences of disability. Future research may begin by conducting foundational research to explore ***what*** autonomous agency means in *having a disability*, *being disabled*, and *living with disability*. Next, this line of research can be advanced by conducting early-stage and exploratory research on ***how*** individuals with acquired disabilities exercise autonomous agency in *having a disability*, ***how*** this influences their perceptions and acceptance of *being disabled*, and ***how*** it affects their appraisal and response to challenges they face in *living with disability*. When integrated with established theories and empirical evidence, the results of this research may produce practical recommendations that encourage rehabilitation professionals to view acquired disability not merely as a clinical condition but as a complex, subjective experience shaped by individual agency, personal circumstances, and social contexts.

7.5.7. Conclusion

Existing research on the psychosocial adaptation experiences of women athletes who have disabilities from acquiring a SCI has remained limited (see Zike et al., 2024). This is problematic, as acquiring a SCI has significant implications for women athletes who face distinct societal challenges due to the intersection of various systems of oppression. This study employed a Photovoice approach (Wang & Burris, 1997), addressing the limitations of previous research by empowering the marginalized voices of women athletes with disabilities to capture data most meaningful to them through visual images. The findings illustrated seven major themes of elements that shape the everyday life experiences of *having a disability*, *being disabled*, and *living with disability* for women athletes after SCI. These themes emphasize the complexity of the disability experience by highlighting its multidimensional, situational, contextual, and social-relational nature. They also demonstrate the autonomous agency of women athletes as they navigate their daily lives with disabilities. The meanings derived from the themes illustrate the interconnectedness of *having a disability*, *being disabled*, and *living with disability*, stressing the need to understand these components collectively when exploring psychosocial adaptation experiences related to acquired disability.

Chapter VIII: Discussion

8.1. Summary of the Research

The purpose of this research was to explore experiences of psychosocial adaptation to acquired disability in women athletes after SCI. In particular, this research investigated the meaning of (a) *having a disability*, (b) *being disabled*, and (c) *living with disability* in an ableist world. Study one aimed to explore the disability narratives of women athletes after SCI and document the meanings they attribute to experiences of psychosocial adaptation to acquired disability. Study two provided women athletes with SCIs a visual voice to capture the elements that shape their everyday life experience of (a) *having a disability*, (b) *being disabled*, and (c) *living with disability* in the community.

Employing a narrative inquiry approach (Riessman, 2008), study one identified four narrative types: (a) *Attachment to a Nondisabled Past*, (b) *Push for Recovery*, (c) Em*bracing Life Without Embracing Disability*, and (d) *Transformation Through Shared Experience*. Each narrative type underpinned a different story characteristic of participants' experiences in adapting to acquired disability. The four narrative types illustrate the unique challenges faced by women athletes after SCI, as having a disability affected their experiences of womanhood and athletic identity. The narrative types were also found to have characterized *having a disability* as embodying stigma and highlighted the autonomous agency of women athletes in living with a disability. *Being disabled* meant identifying with disability stigma, and *living with disability* was characterized as a multidimensional ongoing process influenced by individuals' desire and attempts to reclaim their pre-SCI lifestyle. The narratives also demonstrated how *having a disability*, *being disabled*, and *living with disability* are social relational. The findings

underscore the collective nature of the acquired disability experience while also emphasizing the uniqueness of each woman's personal narrative. By illustrating the connections between *having a disability*, *being disabled*, and *living with disability*, the research emphasizes the importance of understanding these connections in investigating psychosocial adaptation to acquired disability.

Employing a Photovoice approach (Wang & Burris, 1997), study two captured eight themes that shape participants' everyday life experience of *having a disability*, *being disabled*, and *living with disability* in the community: (a) *Taking Care of the Disabled Body*, (b) *Continuity and Attachment*, (c) *The Disability Tax*, (d) *Adaptations*, (e) *Interpersonal Connections*, (f) *Environmental Accessibility*, and (g) *Feeling Like a Disabled Person*, and (h) *Gratitude*. These themes emphasize the complexity of the disability experience by highlighting it as multidimensional, situational, contextual, and social-relational in nature. The themes also demonstrate the autonomous agency of women athletes as they navigate their daily lives with disabilities. The meanings derived from the themes illustrate the interconnectedness of *having a disability*, *being disabled*, and *living with disability*, stressing the need to understand these components collectively when exploring psychosocial adaptation experiences related to acquired disability.

8.2. Theoretical Contributions

This research contributes to the literature on the intersectionality of being a woman athlete with acquired disability after SCI by demonstrating how *having a disability* affected the participants experiences of womanhood and athletic identity. The findings showed that *having a disability* was viewed as a "discrediting attribute" (Goffman, 1963) by the women in this

research, interfering with their ability to meet societal standards of femininity and invalidating their womanhood in the eyes of others. This aligns with existing literature indicating that men and women with disabilities believe possessing a disabled body prevents them from achieving ideals of femininity and masculinity and raises questions about its deviancy from cultural norms (Reel & Bucciere, 2010). This was further evidenced by the women's stories of body image issues that influenced how they navigated developing romantic relationships and whether they embraced their disabled bodies. Additionally, the findings showed that *having a disability* presented challenges to the women in reclaiming aspects of their athletic lives after SCI and mitigating the loss of athletic identity. Having a disabled body prevented some of the women from seeing themselves as athletes, as they were attached to their previous embodied identities and ways of functioning. This is consistent with a "nonathlete" narrative (Perrier et al., 2014), which suggests physical impairments prevent people with disabilities from seeing themselves as athletes. The findings demonstrated that a key factor in combating disability stigma and facilitating continued participation in sport was seeing and actively engaging with other women athletes with disabilities. These women athletes served as positive role models, and interactions with them helped the women in this study by encouraging them to participate in adaptive sport, connecting them with other adaptive sport athletes, and normalizing *living with disability*.

This research contributes to the literature on *having a disability*, *being disabled*, and *living with disability* by demonstrating several commonalities across the constructs. First, the findings showed that *having a disability* is commonly viewed as a problem of the body that needs to be hidden, a label or identity that one must distance oneself from, and a challenge

that must be overcome. This is consistent with a medical model of disability that portrays disability as a personal flaw located in the body that must be overcome or remedied through medical intervention (Smith & Bundon, 2018). Second, the findings confirm existing literature (e.g., Forber-Pratt & Zape, 2017; Livneh, 2021; WHO, 2001) that suggests *having a disability*, *being disabled*, and *living with disability* are multidimensional in nature, as the women's narratives and images illustrated how each construct was the product of the interplay between individual, internal factors, and the social environment. Third, the findings indicate that each construct is dynamic in nature, as its meaning constantly changes depending on the situation, context, and relationship with the social environment. This aligns with existing literature (Forber-Pratt & Zape, 2017; Kendall & Buys, 1998; Thomas, 1999) that characterizes *having a disability*, *being disabled*, and *living with disability* as constantly changing through a process of continued interaction with the social environment. Fourth, the findings highlight the positive aspects of both *being disabled* and *living with a disability*, as they were characterized by positive attributes (e.g., adaptability, creativity, patience, strength) or outcomes (e.g., creating opportunities, fostering relationships, leading to joy). This supports an alternative affirmative perspective that views disability as a positive aspect of social identity and a natural form of diversity (Swain & French, 2000), celebrating it as something that enriches life rather than as a misfortune that needs to be changed.

This research also makes unique contributions to the literature of each construct. First, the findings add to the literature by demonstrating how individuals exercise autonomous (rather than passive) agency in *having a disability*. While prior research (e.g., Oliver, 1990; Thomas, 1999; WHO, 2001) has treated people with disabilities as passive agents and

conceptualized disability as something that happens to you, these findings extend existing theory (Thomas, 1999) by showing how the women acted independently and made their own choices to achieve their goals, even within social constraints and norms. This underscores the women's psychological freedom to make their own decisions and act upon them. Second, the findings add to the literature by demonstrating how *being disabled* is influenced by social context. When the women were with others who had disabilities, *being disabled* was normalized and accepted. It was also less psychosocially intrusive, which allowed for comfortable discussions about disability. In contrast, when the women interacted with nondisabled individuals or were in situations that highlighted their disabilities in a disruptive way, this led to discomfort and made them want to distance themselves from *being disabled*. The findings are consistent with existing literature on *being disabled* (Caldwell, 2011; Dunn & Burcaw, 2013; Forber-Pratt & Zape, 2017; Gibson, 2006; Gill, 1997), which highlights the importance of connecting with others who have disabilities to integrate disability into one's self-concept. They also support prior research that shows certain identities become more salient depending on the situation (Stryker & Serpe, 1982, 1994) and context (Dunn & Burcaw, 2013). Furthermore, these findings reinforce the idea that social identity is both relational and situational (Eriksen, 2001), affected by interactions within the social environment (Gee, 2001; Mead, 1934). Third, the findings add to the literature by demonstrating that *living with disability* is an ongoing, dynamic process. The findings provide evidence that the adaptation process to acquired disability continues throughout a person's life. While existing theories are inconclusive on whether adaptation leads to a final outcome or continues throughout life

(Livneh, 1991; Vash & Crewe, 2003), this research supports Kendall and Buys (1998), who argue *living with disability* is an ongoing process of adaptation throughout the lifespan.

The major finding from this research is that *having a disability*, *being disabled*, and *living with disability* are interconnected. Collectively, the findings from studies one and two indicated that the way the women perceived *having a disability* affected their understanding of what it meant to *be disabled*, as well as their inclination to embrace or resist a disability identity. The findings also indicated that the meaning of *having a disability* influenced the resources available for and the outcomes of *living with disability*. The way the women perceived *having a disability* impacted their willingness to connect with other disabled individuals and affected whether they embraced or restricted their use of assistive technology. Additionally, the extra effort needed to manage *having a disability* affected the outcomes of *living with disability*, including psychological and financial well-being. What it means to *be disabled* was shown to affect *living with disability,* as the women's perceptions of *being disabled* were found to affect whether they distanced themselves from the disability community and focused on trying to completely recover. Furthermore, the findings demonstrate that the factors affecting *living with disability* influenced *having a disability* and *being disable*d. *Living with disability* was shown to lead to positive thoughts about *having a disability*, as the women came to see how disability enhanced their lives. It was also shown that relationships developed *living with disability* contributed to how *being disabled* was viewed and whether it was integrated into the self-concept. In the existing literature, *having a disability*, *being disabled*, and *living with disability* have been studied independently. The findings from this research indicate that these constructs are not separate from each other, nor should they be, as neither of the constructs tell the whole story

of these women's experience of psychosocial adaptation to acquired disability on its own. As such, future investigations of *having a disability*, *being disabled*, and *living with disability* should not be conducted in isolation from each other.

Taking a further birds-eye view, when looking at the research findings, there's evidence to suggest that *having a disability*, *being disabled*, and *living with disability* are socio-ecological in nature (Bronfenbrenner, 1979; Wadey et al., 2018). At the intrapersonal level, the research findings illustrate how the women's thoughts and feelings related to physical impairment and disability, along with the challenges of navigating constraints imposed by their relationships with the social environment, shaped their adaptation experience. For example, the internalization of disability stigma affected the relationships they developed and their community participation. The findings also highlight an important addition to the intrapersonal level: the internal biophysical reality of impairment. It is not just the cognitive, affective, and behavioral aspects that shape one's internal experience; the women's immutable biophysiological reality is shown to be integral to the disability experience as the women navigated the care and direct impact of the consequences of impairment.

Figure 51

The Socio-Ecological Nature of Having, Being, and Living with Disability

Note. Adapted from Bronfenbrenner (1979) and Wadey et al. (2018).

At the interpersonal level, the research findings highlight how relationships are integral to the meaning of *having a disability*, *being disabled*, and *living with disability* for women athletes with acquired SCI. For example, interactions with both disabled and nondisabled individuals affected individual development across the constructs. Often, social context, shared experiences, and social narratives influenced these relationships and determined whether the impaired body faced social constraints. At the institutional level, the research findings demonstrate the impact of organizational structures on fostering or hindering adaptation. One example of an institutional factor is the women's relationships with the psychosocial architecture of adaptive sport groups. Adaptive sport groups created environments that offered

opportunities and space for social connection or presented disabling social barriers. At the cultural level, the research findings highlight the influence of various cultural narratives, norms, and beliefs on the attitudes and behaviors of the women, as well as their intra- and interpersonal relationships. Certain disability narratives affected how the women approached *living with disability*, and cultural norms rooted in disability stigma impacted how the women perceived *having a disability* and *being disabled*.

At the policy level, the research findings demonstrate the policies and regulations that have influenced the women. Policies that governed the women's community participation, such as the ADA, had substantial effects on how they navigated their community. It was also demonstrated that interpersonal interactions can either interfere with or facilitate the accessibility requirements of these policies. At the temporal level, the research findings show how events and life transitions have influenced and continue to influence the women over time. Various events throughout the women's lifespan with disability, including forced athletic retirement due to SCI and functional decline with aging, were demonstrated to affect how they navigated *living with disability*. The findings indicate a complex interplay among these factors at different levels, suggesting that they interact on multiple levels. This intricate relationship can affect outcomes and decisions in the process of adapting to acquired disability.

8.3. Key Strengths of the Research

This research has multiple strengths. First, it is the first of its kind to integrate all three foci and investigate the relationships among these constructs. By adopting a holistic perspective, this research provides a more comprehensive insight into the complexities of the constructs of *having a disability*, *being disabled*, and *living with disability*. Second, much of the

research across these three foci has been theoretical in nature. This research adds empirical evidence to support and extend the existing research. Third, existing research has conceptualized *having a disability*, *being disabled*, and *living with disability* in isolation from each other, rather than as interconnected elements of the disability experience. This research establishes that these three foci are interconnected and should be understood together. Fourth, women's stories are largely nonexistent in the existing research (Zike et al., 2024). This research adds to the literature on women athletes with SCI. And fifth, the combination of study approaches enhanced the richness and nuance of the data collected, facilitating a holistic examination of the research constructs. By integrating findings from both studies, this research yielded valuable insights that would have remained elusive if each were conducted separately. Without using a Photovoice approach to complement the narrative evidence, it would not have been possible to capture the interconnectedness of the three constructs as thoroughly as the research would have through narrative alone.

8.4. Research Limitations

The limitations of this research reflect those typical in foundational research (ED & NSF, 2013), as the inherent methodological constraints were magnified across two studies. Key limitations include the specificity of the sample and the substantial time and effort required from participants, as dictated by the chosen methodologies. Both the narrative inquiry (Riessman, 2008) and Photovoice (Wang & Burris, 1997) approaches provided valuable insights; however, these approaches are deeply rooted in the specific context of women athletes' experiences with acquired SCIs. Due to the context-specificity of the sample, the research findings cannot be directly applied to other populations. To determine the transferability of the

research findings, further exploration of the interconnections between *having a disability*, *being disabled*, and *living with disability* across diverse samples is necessary (ED & NSF, 2013). Additionally, participant attrition between the two studies may stem from the context-specific demands of the data collection methods used in each study. Photovoice places substantial demands on participants' time and effort due to the tasks they must complete. These demands may have influenced whether the women continued to participate in the study or withdrew. Additionally, those who continued to participate in Study 2 may have opted to fulfill only the minimum requirements of the study tasks. Given these limitations, it is prudent to be cautious when applying the findings to different populations or formulating practice recommendations.

8.5. Future Research

The findings from this research extend existing literature on the psychosocial adaptation to acquired disability by investigating the experience of *having a disability*, *being disabled*, and *living with disability* in a more comprehensive manner than has been done in previous research. These findings enhance our understanding of the connections between these constructs and serve as a basis for future studies aimed at advancing science and clinical practice related to psychosocial adaptation to acquired disability following SCI. Building on these foundational research findings, future research should prioritize early-stage and exploratory research (ED & NSF, 2013) investigations into the relationships among *having a disability*, *being disabled*, and *living with disability*. Exploring ***HOW*** the relationships between these constructs shape psychosocial adaptation outcomes and ***HOW*** social context influences these relationships is essential to understanding the complexities of this phenomenon.

The research findings also highlighted the role of autonomous agency in women athletes' experiences adapting to disability after SCI. To move this line of research forward, future research may conduct foundational research (ED & NSF, 2013) to explore ***WHAT*** exercising autonomous agency means in the context of *having a disability*, *being disabled*, and *living with disability*. This line of research can be advanced through early-stage and exploratory research (ED & NSF, 2013) that focuses on ***HOW*** exercising autonomous agency influences *having a disability*, *being disabled*, and *living with disability.* When this research is integrated with existing theories and empirical evidence, it may yield practical recommendations for rehabilitation professionals that shift perceptions of disability toward an understanding of the complex, subjective nature of the experience and the influence of individual agency and contextual factors. By reframing the conversation around disability in this manner, it may foster a more supportive and empowering environment for individuals, encouraging resilience, self-advocacy, and fulfillment in everyday life.

8.6. Dissemination

The stories and images shared in this research yielded valuable insights into the experience of psychosocial adaptation to acquired disability in women athletes after SCI. It is important that these findings are disseminated in a way that reaches all key stakeholders. Existing research demonstrates various ways to disseminate the findings of narrative research (e.g., ethnodrama; Smith & Sparkes, 2009) and Photovoice research (e.g., classroom discussions, photo exhibitions at conferences, publication on social media; Dassah et al., 2017) to the public, aiming to raise public awareness. This research will disseminate findings in the following ways: (a) photo exhibitions at local (e.g., University of Wisconsin-Milwaukee Partners

for Health Research Symposium) and international conferences (e.g., Association for Applied Sport Psychology annual conference), (b) publication on social media (e.g., Instagram & LinkedIn), (c) publication in peer-reviewed academic journals (e.g., *Disability and Rehabilitation*, *Rehabilitation Psychology*), and (d) classroom discussions in sport psychology and disability related courses. Through these methods, the research will aim to reach the various stakeholders in this research (e.g., women athletes with acquired disabilities; general population; rehabilitation professionals; academic researchers in the fields of disability, sport, and rehabilitation; applied practitioners, and university students pursuing careers in disability, sport, and rehabilitation). In disseminating this research, the authors will emphasize the stories and images shared by the women in this study to create visual representations that highlight their unique experiences.

8.7. Conclusion

Acquiring a SCI has significant implications for women athletes, as they face distinct societal challenges while adapting to acquired disability due to the intersection of various systems of oppression, such as ableism and sexism. Although there exists a body of research examining the psychosocial adaptation experiences of athletes following a SCI (see Zike et al., 2024), studies specifically focusing on the disability experiences of women athletes who have SCIs has remained limited. This research explored the psychosocial adaptation experiences of women athletes who have acquired a disability due to SCI. In particular, this research investigated the meanings associated with (a) *having a disability*, (b) *being disabled*, and (c) *living with disability* within an ableist society. Employing a mixed methodology, the first study utilized a narrative inquiry approach (Riessman, 2008), while the second study used the

Photovoice approach (Wang & Burris, 1997). The findings from this research provided valuable insights into the psychosocial adaptation experiences of women athletes with disabilities. The novel approach to investigate the interrelations among the constructs of having, being, and living with disability, collectively, rather than isolation, contributed to a multidimensional understanding of the phenomenon and emphasized the importance of understanding the relationships between these constructs.

Chapter IX: Reflection

My position is that of a disabled, white, heterosexual, cisgender man with a personal history of acquired sporting SCI. For me, *having a disability* means existing in an impaired body, which I use to act, communicate with others, and experience the world. I identify as a disabled person because disability is an inextricable part of my identity and holds value for me. *Being disabled* shapes my self-perception, my body image, and my interactions with social and physical environments. Living with an acquired disability means I have experienced life as a nondisabled person and continue to adapt to my disability and strive for acceptance and access. It is through this lens that I now reflect on my experiences as a researcher in this research process.

As a researcher with a disability, I possess an insider's perspective on the disability experience. Because I have a visible disability, it was more likely that I would be treated as an insider by the women who participated in this research. Throughout the research process, I found that my SCI experience helped me relate to the participants and enabled me to obtain more insightful responses. The women often commented that they did not know if they would have been as forthcoming about their experiences if I were not also a person with an acquired disability after SCI. They believed they would not have been as comfortable revealing some of the more intimate details about their disability experience with a nondisabled researcher.

Given my understanding of the various barriers and facilitators affecting the research process as a person with a SCI, I was conscious of the challenges that might hinder an individual's participation and how to effectively support their involvement. As part of my data collection methods, I asked participants to choose between a disposable camera or their

personal devices to capture their experiences. All participants opted to use a personal device, and I believe that this option allowed them to better meet the data collection goals. Furthermore, using personal devices gave participants greater control over what data to capture and discuss.

As a cisgender man, there was a distinct difference between the research participants and me. I possess an outsider's perspective on the experience of being a woman with an acquired disability after SCI, and I had the impression from my interviews that my gender may have limited some of the discussion related to their gendered experience of womanhood with a disability after SCI. However, there were several women who were particularly revealing in their discussions of their bodies, caring for their bodies, sexuality, and intimate details about their relationships. My initial interpretations of the data also demonstrated the impact of my outsider's perspective, as I believe the lack of sensitivity to the experiences of women with disabilities led to challenges in capturing the meaning in their stories and images. It was only upon further reflection that I was able to recognize my mistakes and better capture the intersectionality of the women's experiences.

I approached the research process believing that my identity and background could foster connections with participants through shared experiences. However, I was concerned that this comfort might hinder data collection, as the women might not feel the need to explain their experiences as thoroughly to me, potentially omitting crucial details I might not grasp. This was evident in some of the interviews as the women would sometimes comment, "you know what I mean," when discussing a topic that they had difficulty expressing. As an interviewer, I attempted to recognize these moments and probe deeper or ask alternative clarifying

questions to give the women opportunities to elucidate the meaning they were attempting to convey.

To mitigate concerns that my positionality might unduly affect the research process, I implemented several strategies. During data collection, I engaged in reciprocity by sharing aspects of my story related to my disability and SCI. By revealing aspects of my experience, I found that it gave me, the researcher, credibility in the eyes of the participants, which facilitated greater rapport during the data collection procedures. I believe this also affected how forthcoming they were about their experiences. I maintained a reflexive diary, which provided me with opportunities to document and reflect on my thoughts during both data collection and data analysis. The diary enabled me to make observations about the interviews. One of these observations was of how certain shared experiences influenced my approach to specific questions. At times, these experiences informed whether I prompted further investigation of a topic or moved on to the next. There were certain responses that I found difficult to reconcile with my own experience and understanding of disability. In these circumstances, I was mindful of remaining open to their responses and allowing them to elaborate on their experiences and understanding.

During data analysis, I recognized that having a disability could affect how I interpreted others' accounts, making me sensitive to certain aspects of this experience while overlooking others. I engaged in peer debriefing to ensure my interpretations of the data were plausible and defensible. My critical friend, who was a woman with a disability and who was not involved in data collection, reviewed the transcripts and lists of themes and was encouraged to question and explore alternative interpretive possibilities. My discussions with my critical friend were

invaluable; they fostered reflexivity and provided me with opportunities to defend my interpretations. This dialogue also helped ensure that my perspective did not unduly influence the results or misrepresent the data shared by participants.

Through this research, I have come to recognize the impact this process has had on me as a researcher. This process has sharpened my skills in not only conducting every element of the research process, but it has also improved my abilities as a writer. I have developed a thorough understanding of designing and implementing studies, analyzing data, and critically reviewing literature. Moreover, I have learned to articulate my findings more clearly and persuasively, thereby improving my ability to communicate complex ideas effectively to diverse audiences. However, the most significant impact this process has had on my development as a researcher is that I now possess a deep understanding of the challenges researchers with disabilities face throughout the process and how to adapt to remain effective as a researcher.

There are several ways in which *having a disability*, *being disabled*, and *living with disability* impacted my work as a researcher in the research process. However, my biggest personal takeaway after conducting this research is that possessing a disability can be a great asset for a researcher. My unique perspective has aided in critically reviewing the literature, designing the research, and interpreting the data. The problem-solving skills I have developed while living with disability have enhanced my ability to approach research questions in unconventional ways, as evidenced by the unique combination of research methods employed to capture the findings of this research. My experience with disability has also fostered a deeper understanding of and empathy for the challenges faced by various populations, which can lead to more insightful research outcomes. The resilience and adaptability that I have

cultivated through navigating the complexities of the disability experience have empowered me as a researcher to overcome obstacles in my work and the research environment, ultimately allowing me to make valuable contributions to my field.

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Appendix A: Eligibility Survey

You are being invited to participate in research examining stories of disability by women athletes after spinal cord injury.

The purpose of this research is to explore experiences of psychosocial adaptation to acquired disability in women athletes after spinal cord injury. In particular, this research will investigate what it means to (a) have a disability, (b) be disabled, and (c) live with disability in an ableist world.

If you wish to participate, please answer the questions below to determine your eligibility. If you are determined to be eligible to participate, you will be contacted via email in the coming weeks with information on informed consent and directions for participation.

Thank you.

Section 1: Eligibility Information

1. To which gender identity do you most identify?
   - Woman
   - Non-binary
   - Man
   - Prefer to self-describe, below
     Self-describe: Text entry

[Skip Logic: Skip to 'End of Survey' if Man or Non-Binary is Selected]

2. What is your age?
   - Text entry

[Skip Logic: Skip to 'End of Survey' if 'What is your age?' is Less Than 18]

3. Do you live in the United States?
   - Yes
   - No

[Skip Logic: Skip to 'End of Survey' if No is Selected]

4. Do you speak conversational English (i.e., language used by everyday speakers)?
   - Yes
   - No

[Skip Logic: Skip to 'End of Survey' if No is Selected]

5. When did your spinal cord injury occur?
   - Text entry [date format: mm/yyyy]

6. Did you have a pre-existing diagnosed disability before the spinal cord injury?
   - Yes

- No

[Skip Logic: Skip to 'End of Survey' if Yes is Selected]

7. Do you have a serious diagnosable psychological disorder/psychiatric impairment (i.e., a diagnosable mental, behavioral, or emotional disorder that causes serious functional impairment that substantially interferes with or limits one or more major life activities)?
   - Yes
   - No

[Skip Logic: Skip to 'End of Survey' if Yes is Selected]

8. At the time of your injury, were you an active participant in sport(s)? (This does not necessarily mean that you were injured while participating in sport)
   - Yes
   - No

Section 2: Contact Information

Participants in this research will complete two online interviews via Microsoft TEAMS and use a camera and an electronic logbook to capture 27 photographs over a two-week photo-taking period. Upon completing the research, you will receive a $50 electronic Visa gift card.

9. If you are interested in participating in this research please provide your contact information:
   - Name: Text entry
   - Address: Text entry
   - Email: Text entry
   - Phone: Text entry

10. If you consent to be contacted by the researcher at the contact information provided please type your name below.
    - Text entry

SUBMIT

[If a participant is determined to be ineligible to participate based on any one of the questions answered, they will be automatically routed to the end of the survey.]

End of Survey Page

Thank you for your interest in this research. If you were redirected to this page before completing the survey, then one or more of your answers to the survey questions indicated that you are ineligible to participate in this research. If you believe you arrived at this page by mistake please contact the researcher using the below information.

If you are determined eligible to participate in this research, the researcher will contact you using the provided contact information.

If you have any questions about the research, please do not hesitate to email or call.

Derek Michael Zike
Principal Investigator
Email: dmzike@uwm.edu
Phone: (317) 656-1558

Appendix B: Demographics Survey

The purpose of this research is to explore experiences of psychosocial adaptation to acquired disability in women athletes after spinal cord injury. In particular, this research will investigate what it means to (a) have a disability, (b) be disabled, and (c) live with disability in an ableist world.

Please answer the questions below to provide information about yourself, your injury, and your sport participation.

Thank you.

Section 1: Demographic Information

1. Are you of Hispanic, Latino, or Spanish origin?
    - No, not of Hispanic, Latino, or Spanish origin
    - Yes, Mexican, Mexican Am., Chicano
    - Yes, Puerto Rican
    - Yes, Cuban
    - Yes, another Hispanic, Latino, or Spanish origin
    - Rather not say

2. What would you describe as your race?
    - White
    - Black or African American
    - American Indian or Alaska Native
    - Chinese
    - Vietnamese
    - Native Hawaiian
    - Filipino
    - Korean
    - Samoan
    - Asian Indian
    - Japanese
    - Chamorro
    - Some other race
    - Rather not say

3. How did you acquire a spinal cord injury?
    - Motor Vehicle Accident
    - Fall
    - Violence
    - Sport
    - Medical/surgical
    - Other

4. What sport(s) were you participating in at the time of your injury?
    - Text entry

5. How many years had you participated in sport before your injury?
  - Text entry

6. What level of sport were you participating in at the time of injury (e.g., high school, collegiate, non-school-based competitive sports league, elite, intramural, etc.)?
  - Text entry

7. At the time of your injury, did you identify as an athlete?
  - Yes
  - No

Section 2: Camera Information

Participants in this research will use a camera and an electronic logbook to capture 27 photographs over a two-week photo-taking period.

8. It is imperative that each participant is comfortable using a camera to capture photographs for this project. The researcher is prepared to mail a disposable camera to participants to complete this task, but if the participant believes they would be better able to capture photographs using their camera phone or digital camera they may elect to do so. Please consider your capabilities and resources and indicate your preference of camera below.
  - Disposable camera (Kodak 35mm Single Use Camera)
  - Personal camera phone or digital camera

SUBMIT

End of Survey Page

Thank you for completing this survey. The researcher will contact you using the provided contact information with further details.

If you have any questions about the research, please do not hesitate to email or call.

Derek Michael Zike
Principal Investigator
Email: dmzike@uwm.edu
Phone: (317) 656-1558

Appendix C: Semi-Structured Interview Guide 1

Pre-Interview Prompts

In this interview, we will be covering what it means (a) to have a disabled body, (b) to identify as a person with a disability, and (c) to live day-to-day with a disability. We are interested in hearing your stories. Please think about your stories of disability and spinal cord injury and come prepared to share them. Below you will find a few story prompts to consider.

- Stories that illustrate what your sport experience meant to you before spinal cord injury
- Stories about your life after spinal cord injury (examples: education, career, sport)
- Stories from your day-to-day life with a disability
- Stories about your relationship with your body and how it has changed since your injury
- Stories about your engagement with (or avoidance of) other people with disabilities, the disability community at large, and disability sport
- Positive stories about disability
- Negative stories about disability

Instructions:

Begin by reviewing (select) Qualtrics responses with the participant. This will serve a dual purpose: to confirm the accuracy of the responses in Qualtrics and to act as an icebreaker to the interview.

Warnings:

- Let them tell their story
- Refrain from asking follow-up questions to tick a box or validate a response based on some preconceived theory
- Reveal only enough about your experience to return them to their story. We are not here for your story.

Life Before and After Spinal Cord Injury Questions

1. Tell me about your life before your spinal cord injury.

   Prompt:

   - *How satisfied were you with your life?*
   - *What were your most valued relationships?*

2. Tell me about your experience in sport before your spinal cord injury.

   Prompt:

   - *What sport(s) were you participating in?*
   - *What level of sport did you compete at?*
   - *What stories do you have from your sport experience that illustrate what that experience meant to you?*
   - *What was your experience as a woman athlete?*
   - *What sport aspirations did you have?*
   - *How much of your life revolved around sport?*
   - *What did you learn from your sport experience?*

3. Tell me about your spinal cord injury experience. Please describe what happened.

   Prompt:

   - *When did your spinal cord injury occur?*
   - *What happened after?*
   - *What were your thoughts and feelings during this period?*
   - *What level was your injury?*

4. Tell me about your life after spinal cord injury (e.g., education, career, relationships).

   - *How was your transition home?*
   - *Tell me about your rehabilitation experience.*
   - *How did you approach your recovery/rehabilitation?*
   - *What affect did your spinal cord injury have on getting an education, a job, etc.?*

5. How have you dealt with the loss of nondisabled sport (as a valued activity)?

   - *How did the loss of sport affect you?*
   - *What effect did your sport experience prior to injury have on your life after SCI?*
   - *Why did you (not) participate in disability sport?*

Living (with Disability)

Spinal cord injury is a significant change event in a person's life. The change brought on by spinal cord injury can significantly affect how we navigate the world. This change begins a process of responding to impairment and disability. The theme of **Living with Disability** is about this process of adaptation. The

goal in asking this series of questions is to find out what it means to you to live with an acquired disability in an ableist society.

1. Tell me about your day-to-day life with a disability.

   Prompt:

   - *How has acquiring a disability affected your life?*

2. Tell me about how you have adapted to living with a disability.

   Prompt:

   - *What has had an impact on the way you have responded to your disability? In what way?*

3. Tell me a story about how your environment (e.g., home, community, school, and workplace) has affected you as a person with a disability.

   Prompt:

   - *How you feel, or act.*

4. How have other people (e.g., friends, family, caregivers, and people with disabilities) affected how you have adapted to living with disability?

   Prompt:

   - *How you feel, or act? Can you give me an example?*

5. How has acquiring a disability changed your relationship with the people in your life?

   Prompt:

   - *How you relate to/or interact with them?*
   - *What are your most valued relationships now?*

6. Tell me a story about when you were reminded of, or were particularly aware of, your disability?

   Prompt:

   - *What did you think, feel, act?*

7. Tell me a story about life as a woman with a disability.

   Prompt:

   - *How have you adapted to life as a woman with a disability?*

8. What are the positive aspects of living with disability?

   Prompt:

   - *How has disability affected your life in a positive way?*

9. What are the negative aspects of living with disability?

   Prompt:

- *How has disability affected your life in a negative way?*

Having (a Disability)

The change brought on by spinal cord injury can be the catalyst for significant changes to one's body as well as the relationship one has with their body. The theme of **Having a Disability** is all about the body. It is about the meaning that a person with a disability as well as society assigns to the disabled body. The goal in asking this series of questions is to find out what it means to you to have a disabled body in an ableist society.

1. Tell me what having a disability means to you.

   Prompt:

   - *How do you feel about having a disability?*
   - *How have your thoughts or feelings about having a disability changed since your injury?*

2. How has your environment affected how you view/think about having a disability?
3. How have other people (e.g., friends, family, caregivers, other people with disabilities) affected how you view/think about having a disability?

   Prompt:

   - *Can you give me an example?*
   - *How have your valued relationships influenced your thoughts/feelings about disability?*

4. How has having a disabled body affected you as a woman?
5. How has having a disability affected your relationship with sport?

   Prompt:

   - *How has your sport experience affected how you view having a disability?*

6. How has having a disability affected your relationship with your body?

   Prompt:

   - *As a former nondisabled woman athlete, how do you see your body since your injury?*
   - *What do you think of these changes?*

7. Tell me a story about your experience with prejudice, stereotyping, or discrimination as a result of having a disability.

Being (Disabled)

The change brought on by spinal cord injury can also significantly affect one's sense of self and the many identities that one may hold. The theme of **being disabled** is about identity. It is about the meaning we

assign to disability identity and how that affects our relationship with our self, others, and our environment. The goal in asking this series of questions is to find out what it means to you to be disabled in an ableist society.

1. How would you identify yourself?

   Prompt:

   - *Think about things like gender, ability, nationality, sexuality, religion, roles (i.e., athlete).*

2. How has disability changed how you see yourself?

   Prompt:

   - *How do you see yourself now compared to before your disability? What has changed?*

3. How have other people or your environment affected how you see yourself?
4. Do you still identify as an athlete? If yes or no, why?
5. What does it mean to identify as a person with a disability/disabled person?

   Prompt:

   - *What are the characteristics and behaviors of a person with a disability/disabled person?*

6. How might having a disability conflict with other held identities such as woman, athlete, mother, partner, etc. (i.e., past, present)?
7. What does it mean to be a woman with a disability?

   Prompt:

   - *What have you learned from other women with disabilities?*

8. Tell me about your involvement in (or avoidance of) the disability community.

   Prompt:

   - *Have you had any difficulty with identifying/associating with disability?*
   - *Tell me about what or who influenced your involvement.*

9. Tell me about your advocacy, activism, and/or political involvement related to disability since your injury.

Concluding Question

1. Are there any other stories about your experience with your disability that you want to share?

Appendix D: Photograph Guidance

Select photographs of landscapes/objects/people/situations/symbols that best represent your views on:

- What it means to have a disability
- What it means to be a woman with a disability
- What it means to be a woman athlete after spinal cord injury
- What makes (or does not make) you feel like a disabled person
- What has shaped your experience living with disability

You are required to take at least one picture of each individual theme for a minimum of five photographs taken. In your electronic logbook, please make note of which theme is associated with each particular photo. To provide further information on the circumstances surrounding each photograph, include a short (2-3 sentence) written narrative in your electronic logbook that includes details on, and the meaning of, each photograph. For example: What is really happening in this photograph? What led you to take this photograph? What is the surrounding context?

Please exclude personally identifying information about others in your written narratives (e.g., names). Personally identifying information refers to any representation of information that permits the identity of an individual to whom the information applies to be reasonably inferred by either direct or indirect means.

Instructions for Taking Photographs of Other People

- You are permitted and encouraged to take photographs of other people.
- By taking a photo of another person, that person being photographed is now a research subject as well.
- It is a violation of privacy to take someone's photo without obtaining their consent. Even if the person did not appear to object, not asking permission may cause that person to be upset.
- Photographs that contain identifying information of either you or a subject will not be included in any publications of this research.

How to Appropriately Obtain Consent from Others

- Consent is very important for the success of photovoice.

- Consent occurs when a person understands all of the benefits and risks of participating in a project, and they give permission to participate.
- Receiving consent from all subjects reduces feelings of intrusion. By asking for consent before taking photos, privacy is not violated, and safety is maintained.
- To ensure that photographs are taken ethically and with consent, you must receive written consent from any subjects before taking any photographs of people's faces or anything that may be used to identify them.
- A general rule to follow is that it is not an invasion of privacy to take a photograph of a group of people where individual faces are not recognizable, or the photographer is taking a photo of something and a person just happens to walk into the shot by accident. In these scenarios, you are not required to receive a signature.
- By asking for consent, the subject gains trust in the photographer and gives a chance for the photographer to discuss what they are doing and explain the photovoice project.
- Consent must be granted before the photograph is taken, even if the photographer believes they will lose naturalness or authenticity. You may wait until the subjects have forgotten you are there so that naturalness is returned.
- What should you do if someone does not want their photograph taken? Some people may not want their photograph taken and will have individual reasons for this. Do not pressure someone. People often feel protective of their community or identity and for this reason may not want their photograph to be taken.
- You will have received a link to the subject consent form that you will use with the people you wish to photograph in an email sent to you. This consent form is on Qualtrics. You may send this link to potential subjects. Subjects must click on this link and then read and sign this form. Once they provide their signature and click submit, consent will be obtained. A copy of these signed forms will be kept by the researcher.

Photo-Taking Safety

- Safety should be a priority for the photographer and subject.
- Do not take a photo of someone doing something risky or incriminating and do not travel to any area that is known to be dangerous just for a photograph.
- Do not do anything you wouldn't usually do. You are not to take any more risk than you would in your everyday life.

- Do not go anywhere you usually wouldn't go and be aware of your surroundings.

Please refrain from taking pictures of anything illegal (i.e. drug use).

Appendix E: Semi-Structured Interview Guide 2

As each photograph is reviewed, the interviewer will ask the following questions:

1. What do you see here in this photograph?

   Prompt: Describe what you see.

2. Tell me the story of this photograph.

   Prompt: How did this photograph come about? Give me the surrounding context.

3. What is meaningful to you about this photograph?

   Prompt: Why was it important to take this photograph?

4. What aspects of your disability experience are represented here?

   Prompt: home, job/school,, activities, interests, relationships

5. What theme is represented here?

   a. If "What it means to have a disability," what does this photograph say about having a disability?

   b. If "What it means to be a woman with a disability," what does this photograph say about being a woman with a disability?

   c. If "What it means to be a woman athlete after spinal cord injury," how does this photograph illustrate what it means to be a woman athlete after spinal cord injury?

   d. If "What makes (or does not make) you feel like a disabled person," how does this photograph illustrate what makes (or does not make) you feel like a disabled person?

      Prompt: How does this depict how you see yourself?

   e. If "What has shaped your experience living with disability," how does this photograph illustrate what has shaped your experience living with disability?

      Prompt: In what way? How has that affected you?

Appendix F: Feedback Questionnaire

Pre-interview questions will be asked before the initial semi-structured interview. They will be used to obtain information about the recruitment materials.

Pre-Interview Questions

1. How relevant do you believe the eligibility survey questions were to this study?
2. How relevant do you believe the eligibility survey questions were to establishing participant eligibility?
3. Are there any modifications that you believe we should make to the survey questions?
4. Was the informed consent form easy to understand?
5. Do you have any questions about the study that were not answered in the recruitment materials (i.e., email invitation, eligibility survey, informed consent form)?

Post-interview questions will be asked following both semi-structured interviews. They will be used to assess and refine the interview questions and protocol.

Post-Interview Questions

1. How would you describe the quality of the questions you were asked during this interview?
   Prompt: were they good, fair, poor, unclear, difficult to understand, confusing, too many, too much overlap?
2. How could we improve the interview questions?
   Prompt: what would you change, modify?
3. Are there any additional questions that might have gained better insight into the issues we discussed?
4. Did you have any questions about the questions asked during this interview?
5. Was the purpose of the interview clear?
6. What is your opinion of my, the researcher's, conduct as an interviewer?
   Prompt: how I asked/introduced questions? How I asked follow-up questions? How I listened? My strengths/weaknesses?

Photovoice-Specific Questions

1. Did you have any questions about the photo-taking process?
2. Were there any issues with the photo-taking process?
3. How could the photo-taking process be improved?

Appendix G: Pilot Study Email Invitation

Dear Potential Participant,

This letter is meant to inform you about a research project examining the stories women athletes who have acquired a spinal cord injury tell about their experiences of psychosocial adaptation to acquired disability and the elements that shape their everyday life experiences. This research is being conducted at the University of Wisconsin-Milwaukee. You are being contacted because the [Collaborating Site] identified you as being potentially eligible.

The purpose of this research is to explore experiences of psychosocial adaptation to acquired disability in women athletes after spinal cord injury. In particular, this research will investigate what it means to (a) have a disability, (b) be disabled, and (c) live with disability in an ableist world. You may be eligible for this research if you:

- Self-identify as a woman
- Are 18 years of age or older
- Live within the United States of America
- Acquired an acquired disability from spinal cord injury
- Participated in competitive organized sport at the time of spinal cord injury
- It has been at least two years since the date of your injury

Participants will complete two online interviews via Microsoft TEAMS and use a disposable camera and electronic logbook to capture 27 photographs. Upon completing the research, you will receive a $50 electronic Visa gift card.

If you are interested in participating in this research, please scan the QR code below (or follow this URL link) and complete the eligibility survey. If you have questions please email dmzike@uwm.edu.

Please note that your participation in this research is voluntary. Whether or not you participate in this research will not affect your relationship with the [Collaborating Site]. You do not have to respond if you

are not interested in this research. If you do not respond, no one will contact you, but you may receive another email that you can simply disregard.

Thank you for your time and consideration. I am looking forward to speaking with you.

Sincerely,

Derek Zike, MS [QR Code here]

Principal Investigator

University of Wisconsin-Milwaukee

[Signature Redacted]

Appendix H: Subject Consent Form

Women Athlete SCI Study

Research Title: Having, Being, and Living: Stories of Disability by Women Athletes After SCI
Researcher: Derek Michael Zike, MS, Doctoral Dissertator, University of Wisconsin-Milwaukee

To be completed by the subject of a photograph

What am I being asked to do?
To provide your consent to take photograph(s) of your face or other personally identifying features or information.

Why are you taking these photographs?
I am taking pictures for a photovoice research project titled " Having, Being, and Living: Stories of Disability by Women Athletes After SCI." This photovoice research project is being conducted to explore experiences of psychosocial adaptation to acquired disability in women athletes after SCI. In particular, this research will investigate what it means to (a) have a disability, (b) be disabled, and (c) live with disability in an ableist world. To reach this goal, participants like myself will use disposable cameras or personal camera devices (e.g. smartphone) in our community to take photographs of people, places, and things that represent my views on:

- What it means to have a disability
- What it means to be a woman with a disability
- What it means to be a woman athlete after spinal cord injury
- What makes (or does not make) you feel like a disabled person
- What has shaped your experience living with disability.

The photographs taken will be used for the purpose of stimulating discussion and illustrating the important ideas. The photographs may also be used in presentations about the project. The names of people who appear in the pictures will not be used or disclosed. Photographs that contain identifying information of either a participant or a subject will not be included in any publications of this research. At the conclusion of the project, the photographs will belong to the researcher and the participants who took them.

Who are the people conducting this project? How can I contact them?
The researcher that is conducting this project is Derek Michael Zike. Derek can be reached via phone at (317) 656-1558 or via email at dmzike@uwm.edu.

How will you use my photograph?
After photographs have been taken, the researcher and participant will discuss each photograph in a photo-sharing interview. Some of the photographs will be included in presentations or publications about the photovoice research project.

Will people know that I had my photograph taken for your project?
To ensure confidentiality, your name or any identifying information will never be mentioned during the discussions we have about photographs. All photographs and identifying information will be maintained in a confidential manner. Data will be stored on computers that are password protected and all data will be secured in a locked file folder.

What will I get out of having my photograph taken for this project?
You will have a chance to help the development of a photovoice research project, a project that will help by increasing awareness of the narratives told by women athletes after SCI and the narrative elements that shape the adaptation experience. This research will also provide a voice to women athletes who have acquired a SCI and the agency to tell their own story. The findings from this research will help guide future research of women with acquired disability.

Do I have to allow you to take my photograph? Can I withdraw my consent to use my photograph if I wish?
You do not have to have your photograph taken. Further, if you decide at a later date that you do not want your photograph discussed or displayed anywhere, you may contact the researcher whose name, email, and phone number is listed above, and your photograph(s) will be removed immediately from the collection. You do not have to give any reason for withdrawing your consent. Remember, your willingness to be photographed is completely voluntary and you may decline at any time.

If you are willing to give your consent to having your (and/or your child's) photograph taken, please fill out the following information and sign the bottom of the form. A copy of the form will be delivered to your email upon submission, in case you have any questions or concerns at a later date.

If subject is under 18 years of age, then the parent or guardian must sign below

Consent
Having read the above information, I _____________________ (printed name) give permission to have my (and/or my child's) photograph taken for purposes of this project. I give unlimited permission to copyright and use the photographs that may include me (and/or my child) in presentations about this project. I have been told that I/my child will not be identified by name or by other background information. I waive any right that I (and/or my child) may have to inspect or approve the publication or use of the pictures.

Signatures
If you have had all your questions answered and would like to have your photograph taken for this research, sign on the lines below. Remember, your consent for photo-taking is voluntarily given, and you're free to withdraw your consent from the research project at any time.

Subject Name ____

Subject Signature ____ Date ______________

If subject is under 18 years old

Parent/Guardian of Subject Name ____

Parent/Guardian of Subject Signature ___________________________Date _______________

Participant Name ____

Participant Signature ____ Date ______________

Appendix I: Collaboration Email

Hello,

My name is Derek Zike and I am a doctoral student at the University of Wisconsin-Milwaukee under the advisement of Dr. Monna Arvinen-Barrow. Currently, I am in a process of preparing my dissertation project titled, “Having, being, and living: Stories of disability by women athletes after spinal cord injury.” The purpose of this research is to explore experiences of psychosocial adaptation to acquired disability in women athletes after spinal cord injury. In particular, this research will investigate what it means to (a) have a disability, (b) be disabled, and (c) live with disability in an ableist world.

I am contacting organizations such as yours to request collaboration in recruiting participants for this research study. Your organization has been identified as one that may be able to facilitate the recruitment of study participants. In this study, the role of your organization as a collaborating site would be to distribute a email invitation to individuals in your database who are eligible for this study.

Please respond to this message and let me know if your organization can assist in the recruitment for this study. Also, please let me know your process or policy for assisting in providing access to potential participants (e.g., Would you require to see IRB approval before and/or after a pilot?).

If you would like further information, please let me know.

Thank you,
Derek

Appendix J: Email Invitation

Dear Potential Participant,

This letter is meant to inform you about a research project examining the stories women athletes who have acquired a spinal cord injury tell about their experiences of psychosocial adaptation to acquired disability and the elements that shape their everyday life experiences. This research is being conducted at the University of Wisconsin-Milwaukee. You are being contacted because the [Collaborating Site] identified you as being potentially eligible.

The purpose of this research is to explore experiences of psychosocial adaptation to acquired disability in women athletes after spinal cord injury. In particular, this research will investigate what it means to (a) have a disability, (b) be disabled, and (c) live with disability in an ableist world. You may be eligible for this research if you:

- Self-identify as a woman
- Are 18 years of age or older
- Live within the United States of America
- Acquired an acquired disability from spinal cord injury
- Participated in competitive organized sport at the time of spinal cord injury
- It has been at least two years since the date of your injury

Participants will complete two online interviews via Microsoft TEAMS. They will also use a camera to capture up to 27 photographs over a period of two weeks, using an electronic logbook to write brief narrative descriptions of the photos they take. Upon completing the research, you will receive a $50 electronic Visa gift card. This research has been approved by the Institutional Review Board (IRB) at the University of Wisconsin-Milwaukee.

If you are interested in participating in this research, please scan the QR code below (or follow the URL link below) and complete the eligibility survey. If you have questions please email dmzike@uwm.edu.

Eligibility Survey Link:

https://milwaukee.qualtrics.com/jfe/form/SV_5uM4E1QhVVCTJxY

Please note that your participation in this research is voluntary. Whether or not you participate in this research will not affect your relationship with the [Collaborating Site]. You do not have to respond if you are not interested in this research. If you do not respond, no one will contact you, but you may receive another email that you can simply disregard.

Thank you for your time and consideration. I am looking forward to speaking with you.

Sincerely,

Derek Zike, MS [QR Code here]

Principal Investigator

University of Wisconsin-Milwaukee

Appendix K: Initial Contact Script

Hello,

My name is Derek Zike and I am a doctoral student at the University of Wisconsin-Milwaukee. Thank you for your interest in my research.

I am contacting you today because you completed an eligibility survey for my research titled "Having, Being, and Living: Stories of Disability by Women Athletes after Spinal Cord Injury" and indicated your interest in participating.

Based on your responses, you qualify to participate in this research. If you agree to participate in this research, your involvement would include completing two online Microsoft TEAMS-based interviews, taking photographs of your everyday life in between the interviews, and using an electronic logbook to write brief narrative descriptions of the photos you take. The first and second online interview are expected to be 120 minutes and 90 minutes in length, respectively. For the time spent completing the required research tasks, you will receive a $50 electronic Visa gift card.

If you wish to participate in this research please complete the next three steps:

- Please scan the QR code below (or follow the URL link below) and complete the informed consent form. If you have questions please email dmzike@uwm.edu
- Please complete the When2Meet[hyperlink] poll to provide your availability for participating in the first online face-to-face interview. The link can be found below.
- Please complete the demographics survey by following the URL link below.

Informed Consent Form Link:

https://milwaukee.qualtrics.com/jfe/form/SV_5yCGoQ5ahD32RAG

When2Meet Link:

URL

Demographics Survey Link:

https://milwaukee.qualtrics.com/jfe/form/SV_5uKvbfbGxKlXNiK

If you have any questions about the research, or if you need to reschedule your interview time, please do not hesitate to email me or call me at (317) 656-1558.

Thank you again for partnering with us on this important research.

Sincerely,
Derek Zike

Appendix L: Informed Consent Form

Research title	Having, being, and living: Stories of disability by women athletes after SCI
Researcher	Derek Michael Zike, MS, Doctoral Dissertator, Department of Rehabilitation Sciences & Technology Monna Arvinen-Barrow, PhD, CPsychol AFBPsS, UPV sert., Associate Professor, Department of Rehabilitation Sciences & Technology

I'm inviting you to participate in a research project. Participation is completely voluntary. If you agree to participate now, you can always change your mind later. There are no negative consequences, whatever you decide.

What is the purpose of this research?

To explore experiences of psychosocial adaptation to acquired disability in women athletes after SCI . In particular, this research will investigate what it means to (a) have a disability, (b) be disabled, and (c) live with disability in an ableist world.

What will I do?

You will complete two online interviews and use a camera and electronic logbook to capture 27 photographs.

- Initial interview:
  - You will complete an online interview about your experience with spinal cord injury and adapting to your acquired disability.
  - I will ask you questions about your disability experience, how you describe it, and how you see yourself and your disability.
  - The total time will be about 120 minutes
- Camera Orientation Session:
  - I will explain the photovoice process and give basic training on how to use a camera to take photographs.
  - The total time will be about 30 minutes
- Photograph Schedule:
  - I will ask you to use a camera and electronic logbook and capture 27 photographs. You will write a short narrative that goes with each.
  - At the end of two weeks, you will mail the disposable camera back to me in the package I provide.
  - The total time will be two weeks.
- Photo-Sharing Interview:
  - You will complete an online interview in which you will share and discuss the photographs you captured.
  - I will ask you questions about the elements that shape your everyday life experience of (a) having a disability, (b) being disabled, and (c) living with disability in the community.
  - The total time will be about 90 minutes
- Member Check:.
  - You will have the opportunity to review my initial interpretations of your answers to interview questions and provide feedback within two weeks (14 days).

Risks

Possible risks	How we're minimizing these risks
Some questions may be personal or upsetting	You can skip any questions you do not want to answer. It is up to each participant to decide what to disclose in the online interviews.
Photograph-taking risk	You will be taking no more risk than you would in your everyday life activities. Photovoice does not require activities that exceed the risk assumed in your daily life.
Breach of confidentiality (your data being seen by someone who shouldn't have access to it)	• I'll store all electronic data on a password-protected, encrypted computer. • I'll store all paper data in a locked filing cabinet in a locked office. • I'll keep your identifying information separate from your research data, but I'll be able to link it to you by using a pseudonym. I will destroy this link after I finish collecting and analyzing the data.

There may be risks I do not know about yet. Throughout this research, I will tell you if I learn anything that might affect your decision to participate.

Other Research Information

Possible benefits	• There is no identifiable benefit to you individually outside of compensation for participation. You may find the research processes insightful and therapeutic by being able to discuss your experiences openly, but there is no immediate therapeutic intent. • Knowledge generated from this project will help rehabilitation professionals develop goals with clients
Estimated number of participants	8 individuals
How long will it take?	The total time commitment may amount to 4 hours of virtual interviews and discussion and two weeks of independent photography.
Costs	Costs for the research tasks and shipping and returning research materials will be covered by the researcher.
Compensation	$50 electronic Visa gift card Due to UWM policy and IRS regulations, I may have to collect your name, address, social security / tax ID number, and signature to give you this compensation. If you discontinue participation before completing the study, then you will not receive compensation.
Future research	Your data will not be used or shared for any future research studies.
Recordings / Photographs	I will audio/visually record you. The recordings will be used for interview transcription. The recordings will be kept until the

	document connecting the participant's name to their pseudonym is deleted. You will take photographs, potentially of yourself. The photographs will be used for data analysis and dissemination of results. Photographs that contain identifying information of either you or a subject will not be included in any publications of this research. The recording / photography is necessary to this research. If you do not want to be recorded / photographed, you should not be in this research project.
Removal from the Research	In order for the data to be useful, it is important that you complete all research procedures. If you miss an interview and cannot reschedule or fail to complete your photograph tasks, I will have to take you out of the research project. Participants will have the opportunity to withdraw their participation from this research up to the time that the document connecting the participant's name to their pseudonym is deleted. After such time, withdrawal will not be possible.
Funding source	None

Confidentiality and Data Security
I will collect the following identifying information for the research: Your name, address, phone number, and email address to reach you at. This information is necessary so that I can complete data collection materials (e.g., mail research materials, place follow-up phone calls, email important documents).

Where will data be stored?	On my computer or in a locked filing cabinet in my office at UWM
How long will it be kept?	Until 1 year after the project period ends

Who can see my data?	**Why?**	**Type of data**
The researchers	To conduct the research and analyze the data	Coded - Identifiers are collected and stored separately from research data, but a key exists to link data to identifiable information.
The IRB (Institutional Review Board) at UWM The Office for Human Research Protections (OHRP) or other federal agencies	To ensure we are following laws and ethical guidelines	Coded - Identifiers are collected and stored separately from research data, but a key exists to link data to identifiable information.

Anyone (public)	If we share our findings in publications or presentations	• Coded - Identifiers are collected and stored separately from research data, but a key exists to link data to identifiable information. • If I quote you, I will use a pseudonym (fake name)

Mandated Reporting

I'm a mandated reporter. This means that if I learn or suspect that a child is being abused or neglected, I'm required to report this to the authorities.

Contact information:

For questions about the research	Derek Michael Zike	317-656-1558 / dmzike@uwm.edu
For questions about your rights as a research participant	IRB (Institutional Review Board; provides ethics oversight)	414-662-3544 / irbinfo@uwm.edu
For complaints or problems	Derek Michael Zike	317-656-1558 / dmzike@uwm.edu
	Monna Arvinen-Barrow	414-251-7428 / arvinenb@uwm.edu
	IRB	414-662-3544 / irbinfo@uwm.edu

Signatures

If you have had all your questions answered and would like to participate in this research, sign on the lines below. Remember, your participation is completely voluntary, and you're free to withdraw from the research project at any time.

____

Name of Participant (print)

____ ______________

Signature of Participant Date

If the participant requires a Legally Authorized Representative:

____

Name of Parent, Guardian, or Legally Authorized Representative (print)

____ ______________

Signature of Parent, Guardian, or Legally Authorized Representative Date

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____

Name of Researcher obtaining consent (print)

Signature of Researcher obtaining consent | Date

Appendix M: Conclusion Script

Hello [name],

You have completed your participation in the research project.

I would like to thank you for your participation in this project.

Included in this email is a link to your $50 research compensation for completing the research tasks.

Electronic Visa Gift Card
Follow this link: URL [hyperlink to gift card]

You will be sent results from the study when all data have been collected and analyzed. I sincerely appreciate your partnering with me on this project.

If you have any questions or concerns, please feel free to contact me at dmzike@uwm.edu or 317-656-1558.

Sincerely,

Derek Zike

Appendix N: Second Contact Script

Hello [name],

I am contacting you today to schedule a date/time to meet face-to-face via Microsoft TEAMS for a virtual introductory session to the photo-taking process.

In the virtual introductory session, I will explain the photo-taking process and we will go over basic training on how to use a camera to take photographs (e.g., how to turn on the flash, and how to use different angles).

[If disposable camera] Before the virtual introductory session, I will ship a single disposable camera to you via USPS Priority Mail. Also included will be an envelope with prepaid postage to be used to return the camera.

To schedule a date/time for a virtual introductory session please provide your availability using the When2Meet[hyperlink] link below:

When2Meet Link:
URL

If you have any questions about the research, or if you need to reschedule your virtual introductory session time, please do not hesitate to email me or call me at (317) 656-1558.

Thank you again for partnering with us on this important research.

Sincerely,

Derek Zike

Appendix O: Introductory Session Follow-Up Script

Hello [name],

Thank you for participating in the virtual introductory session to the photo-taking process.

Attached to this email you will find (a) photograph guidance for photo-taking, (b) the Microsoft PowerPoint slides used in the virtual introductory session, and (c) a document with instructions on how to access and input data into your electronic logbook.

As a reminder of what was discussed today, you have two weeks to take up to 27 photographs, beginning after today's virtual introductory session.

If you have any questions about the research, please do not hesitate to email me or call me at (317) 656-1558.

Thank you again for partnering with us on this important research.

Sincerely,

Derek Zike

Appendix P: Photograph Update Script

[To be completed over phone or email]

Hello [name],

I am contacting you today to discuss your photo-taking and encourage you to complete your photo-taking and electronic logbook entry over these next 7 days.

- How has the photo-taking process been for you?
- How many photographs have you taken?
- Have you experienced any difficulties with photo-taking?
- Do you have anything else of note that you would like to discuss about the research?

As a reminder, you have one more week to complete your photo-taking and electronic logbook entry.

[If disposable camera] At the end of this week, you will mail your disposable camera back to me using the prepaid USPS Priority Mail envelope included with the camera sent to you.

[If personal device] At the end of this week, you will upload your photos to your Microsoft TEAMS folder.

If you have any questions about the research, please do not hesitate to email me or call me at (317) 656-1558.

Thank you again for partnering with us on this important research.

Sincerely,

Derek Zike

Appendix Q: Third Contact Script

Hello [name],

I am contacting you today to schedule a date/time to meet face-to-face via Microsoft TEAMS for the second online interview.

[If disposable camera] Attached to this email you will find an electronic copy of the photograph prints which have also been uploaded to your Microsoft TEAMS folder.

To schedule a date/time for the second online interview please provide your availability using the When2Meet[hyperlink] link below:

When2Meet Link:
URL

If you have any questions about the research, or if you need to reschedule your second online interview time, please do not hesitate to email me or call me at (317) 656-1558.

Thank you again for partnering with us on this important research.

Sincerely,

Derek Zike