

Marginalized Consumers
Exploring Disability, Body Image, and Clothing Consumption

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Vita

Krystal Suzanne Sarcone was born January 14, 1987 in Beacon, New York to Tara Marie and Nicholas John Sarcone. Krystal attended Hendrick Hudson High School in Montrose, New York and Ithaca College in Ithaca, New York. At Ithaca College, Krystal was awarded a scholarship through the Emerson Summer Internship Program to pursue independent research on orphan support systems in northern Morocco. Along with co-principle investigators, Krystal also presented at the James J. Whalen Academic Symposium on a qualitative project looking at worksite wellness. She received a Bachelor of Science degree in Community Health Education in May of 2009. After graduating, she worked in clinical research at the Hospital for Special Surgery in New York, New York. From there Krystal worked as a patient educator and advocate in a network of community health clinics, Open Doors, in Westchester, New York. Krystal also volunteered and worked on a part-time basis with several nonprofits that provide spine surgical expertise and treatment to pediatric patients with significant deformity. Then in September of 2013, she took the position of Executive Director of SpineHope, at one such nonprofit based in Austin. At SpineHope Krystal facilitated the launching of new programs and partnerships around the globe, serving mainly as the primary (and sometimes sole) liaison between volunteer medical professionals, international hospitals, as well as between patients and their families. In September of 2014, Krystal began studies at Brown University to pursue her Master of Public Health with a focus in Global Health. Inspired by ideas originating during her nonprofit work, empowered with the discoveries of her thesis research and with the support of the Center for Entrepreneurship Krystal looks to translate her passion into tangible solutions. Lastly, in June 2017 Krystal will enter the MPA program at Brown, where she hopes to integrate her public health background into policy work in a global context.

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PART 1: LITERATURE REVIEW – DISABILITY, BODY IMAGE AND THE ROLE OF ADAPTIVE ATTIRE

Introduction

Clothing serves a multitude of functions, including meeting legal expectations of attire in public or in work settings, protection from the elements (Civitci, 2004; Chang, 2014), comfort for mobility, thermo-regulation (Karjalainen, 2007; Havenith, 2002; Parsons, 2002) and independence in dressing oneself. Our attire can also symbolically serve as a canvas upon which our personality and capabilities can be displayed, as well as a venue through which we can enhance our self-esteem (Tomas, 2016; McDermott, 2015), or convey our group affiliation (MacDonald, 1994a). As a vital part of our engagement with society, clothing can either hinder or heighten our opportunity to experience normalcy, comfort, positive emotions of self-image, and improved Quality of Life (QoL) (McDermott, 2015). Conversely, dissatisfaction and/or a negative body image has been linked to a risk factor for psychosocial dysfunction (Taleporos, 2002; McDermott, 2015) and negative attitudes towards one's own body (Heider, 2015; Taleporos, 2002).

The purpose of this review is to conduct a formative investigation into the available literature surrounding adaptive attire. Adaptive attire is defined as clothing that has been intentionally and intelligently designed to consider the functional and symbolic needs of people with disabilities (PWDs). Adaptive attire encompasses clothing at the intersection of body image and disability. Adaptive attire has also been called disability clothing, adaptive apparel, or is simply clothing that encompasses universal design concepts, or accommodates the unique needs of its users. Though ample anecdotal evidence exists revealing a need for adaptive clothing, and

the important role clothing has on physical and psycho-social aspects of health, this literature review aims to uncover and share what has been previously published in this realm.

This paper explores the nuances of the theoretical models behind disability itself, the psycho-social impact of clothing and its function, the scientific origins of body image, as well as the beneficial attributes adaptive apparel can provide, or how such attire can be designed to not only eliminate frustration, but improve mobility, enhance functionality, and maximize engagement with society. Thus, the scope of literature investigated here includes topics of disability, body image, concepts of normalcy, clothing, universal design, as well as the complex overlap of each of these domains.

Since the main topics of interest are of concern to people around the globe, literature was considered from any/all locale. However, this review only considered published work and did not consider disability-specific literature for non-physical disabilities.

Overall, the review found that body image and disability are intimately linked and that aspects of both play a role in the health, social engagement and QoL of PWDs. However, much of the previously published literature on body image and disability is couched in the social or medical models of disability and is often conducted with PWDs of spinal cord injury. The literature also documented the need for adaptive attire dating from the 1960s (Behrens, 1963; Frescura, 1963) and revealed the contemporary dissatisfaction of PWDs with limited apparel options (Carroll, 2007) and other clothing barriers to clothing consumption (Kaufman, 1999). Consumption is defined as the process by which we procure and use clothing post purchase (Chang, 2014).

Methods

I conducted this literature review using a hybrid approach including the Brown University library catalogue, Josiah, and web-based search engines specializing in scholarly literature. These sources include WorldCat, PubMed, and Google Scholar. Search terms included *Body Image*, *Disability & Image*, *Disability & Clothing*, and *Apparel & Universal Design*. An initial collection of 86 peer reviewed pieces was compiled; features available through source entities, such as “related articles” and “cited by” were also used to uncover potential pieces related to my topics of interest. Some individual articles brought to light relevant searchable journals such as *Body Image*, or new fields such as Applied Ergonomics.

After an initial review, I eliminated 12 articles with little or no relevance to the topic. I subsequently conducted a more thorough review of individual articles, reading through abstracts and the articles’ core content. The criteria by which decisions were made to eliminate additional articles centered on relatedness and breadth. Some pieces of literature were eliminated if they had too narrow an emphasis on specific disabilities, which I considered to deviate too far from my target concepts. Some published papers in the neuropsychological literature were too technical for the more ethnographic input my research sought to consider during this review.

Of the remaining journal articles, a subset of literature was deemed substantial in its relevance and depth of insight. Serving as critical gateway pieces, an in-depth analysis of their bibliographies was conducted to identify additional helpful resources.

Further valuable resources originated from the suggestions made to me by my thesis advisor, Dr. Renée Shield, my thesis reader Sarah Skeels, MPH, and Dean Terrie Fox Wetle. These sources suggested contemporary pieces on design movements in the realm of adaptive

attire, as well as sociological classics, such as Stigma (Goffman,1963), and critical pieces in the field of disability studies.

It should also be noted that though more recent sources were found and are highlighted in this literature review, no article was excluded simply due to its date of publication. Some superior works related to adaptive attire originate in the 1960s and 1970s (Behrens, 1963; Frescura, 1963; Moran, 1976; Schwab, 1973; Warden, 1975) and their relevance today only further exemplifies the decades-long lack of attention and continued need of this topic.

Review of the literature

To fully appreciate the intention of adaptive attire, the literature surrounding disability and body image will first be explored. A thorough understanding of these cultural constructs will help situate and analyze the function of clothing and explore what has been published on the topic of adaptive attire.

Disability

Disability Defined

“Disability,” as a concept and its rhetoric use, has strong cultural roots that are inextricably bound to historical, political, and geographical contexts (Burch, 2013). In the most biological sense, disability can be broken down into physical, sensory, or mental distinctions and is marked by limitations in body structure, function, or participation. However, Siebers (2011) says that “Disability is not a physical or mental defect but a cultural and minority identity.” According to the ADA, the term *disability* means “with respect to an individual a physical or mental impairment that substantially limits one or more major life activities of such individual; a record of such an impairment; or being regarded as having such an impairment” (ADA, 1990).

Disability can be present at birth or occur later in life and can be experienced acutely or chronically. Not all disabilities are experienced equally by those who have them, and the complexity of disability is a multi-dimensional, and subjective concept.

Prevalence

Despite challenges in defining and counting individuals who are PWDs, PWDs constitute a significant proportion of the population. In 1994, roughly 21% of the USA, or approximately 54 million people, self-reported as having a disability (Kaufman, 1999). Two decades later, those numbers hover around the same percentage (Siebers, 2011), which means that PWDs make up the largest minority population in the United States (Baker, 2006), a proportion expected to rise as people continue to live longer. Globally, nearly 650 million people have disabilities (WHO, 2010). It is also important to highlight that only about 15% of people who have a disability were born with their impairment, revealing that ability based on perfect body function is a temporary state at best (Siebers, 2011).

Disability Theory

Lastly, the concept of disability has been explored and explained through several frameworks over the decades. First, a medical model dominated in which an individual's limitations were approached clinically with the intention to cure and ameliorate the physical condition with little attention given to social and environmental aspects of the disability (Areheart, 2008). As described by Siebers (2011), "The medical model defines disability as an individual defect lodged in the person, a defect that must be cured or eliminated if the person is to achieve full capacity as a human being." The subsequent social model was a direct reaction to

the medical model. More attention focused on the systematic barriers and societal attitudes of exclusion to frame the experience of disability (Areheart, 2008). However, neither model succeeds in capturing the true multi-dimensionality of health and disability.

The International Classification of Functioning, Disability and Health (ICF) Model

In response to the deficits in the models, the World Health Organization (WHO) came to consensus in 2001 on a new biopsychosocial model of disability, known and established as the International Classification of Functioning, Disability and Health (ICF). See Illustration 1. The model is famed for its universality, through establishing a common language and permitting the comparison of data across nations (WHO, 2002). Additionally, the model appropriately considers the dynamic nature of health and disability, and the interplay of biological, personal, societal, and environmental attributes. Previously, disability was thought to “begin where health ended” (WHO, 2002). The ICF model centers less on the etiology of disability, aiming instead to provide a means by which the impact of experiencing a decrement in health, a natural human experience, can be measured (WHO, 2002).

The ICF model is a superior framework not only because it acknowledges the reality that perfect health is unrealistic, but it also provides a context through which research and analysis can be conducted with thorough appreciation for the multi-dimensional attributes of health and disability (WHO, 2002). The model, incorporating facets of *structure* and *function* (essentially anatomy and physiology), *activity* and *participation* with society, as well as contextual factors, both *environmental* and *personal* fosters a more comprehensive approach to researching and evaluating disability and health. The ICF model offers an improved strategy to studying topics around disability because it puts the lived experiences of PWDs into a holistic context. For these

reasons, the ICF model is the main theoretical approach for my thesis work, including both this literature review and the following paper.

Body Image

Body image is a way in which individuals experience body representation, the subjective picture or mental image of one's own body (Tessari, 2010). Body image, as defined by Teal (1975) also involves feelings and attitudes towards one's own body (Taleporos, 2002). Twenty-first century literature states that body image is a construct with cognitive, behavior, and emotional elements as they relate to physical appearance (Cash, 2011; Grogan, 2006; Bailey, 2016) and body function (McDermott, 2015). Since body image has been shown to affect our emotions, thoughts, and behaviors, its role in our everyday lives and its influence on our relationships and overall quality of life should not be minimized (Tomas, 2016).

Early decades of body image research in clinical psychology focused on able-bodied young women with eating disorders (Taleporos, 2002; Grogan, 2006). Since then, multiple fields have approached research on body image from different angles, acknowledging that body image and its consequences are relevant to everyone and go beyond strict concerns of weight and shape (Grogan, 2006).

Disability & Body Image

Though some claim that the role of appearance and body image has been neglected in disability studies (Taleporos, 2002; Lamb, 2001), much of the work by disability scholars has dealt more with the built environment than with “the near, portable environment of dress”

¹ Albeit an imperfect term, ignoring the complexity of ableism, when used “able-bodied” will indicate no apparent, significant or diagnosable physical limitation or disability.

(Lamb, 2001); some research explores the interplay of body image with the social realities of PWDs.

One recent study looked at the issue of stigma and body image when paired with stigma of physical disability (Bailey, 2016). Using a small sample of individuals with spinal cord injuries ($n=9$), body appearance was the most frequently discussed aspect of body image. The majority of participants shared concerns regarding being perceived as “normal,” and seven were preoccupied with mechanisms to improve attractiveness, sharing how they used fashion, make-up and jewelry to hide or accentuate certain of their features (Bailey, 2016).

Earlier research also explored spinal cord injuries for males (Romeo, 1993), and females (Kettl, 1991), and reported that physical disability and injury negatively impacted body perception and satisfaction. In studies with individuals of other diagnoses, such as cerebral palsy, similar sentiments were shared regarding body image and questions of desirability and attractiveness given their disability (Taleporos, 2002).

The qualitative work of Taleporos (2002) also set out to specifically explore body image concerns for PWDs. With a small sample of PWDs ($n=7$), the researchers found that each participant experienced struggles in body image, and reported that negative social attitudes were often internalized. Sentiments and comments of physical inadequacy and unattractiveness permeated participants’ narratives (Taleporos, 2002). Framed in the social model of disability, researchers described that social attitudes, incongruent social ideas, and the process of stigmatization contributed to negative body image.

As is evident from the studies above, body image is a major consideration for PWDs. However, little recent research looks at disability through the biopsychosocial model encouraged by the ICF framework. Further, it seems that the literature on body image and PWDs is centered

around spinal cord injuries with less attention given to the spectrum of disabilities. Lastly, the literature indicates that concepts of *normalcy* and *stigma* are important to consider.

Disability & Normalcy

A societal fixation on notions of normalcy has been more influenced by historical ties and ideals than by human nature; the reality that humans age and experience imperfect health (Millett 2010). Entering the English language in 1840, today the word “normal” implies “that which does not deviate” (Davis, 2010). Those who deviate, who find themselves on the tail ends of a bell-curve distribution are thought of as deviants; and individuals with disabilities are deviants (Davis, 2010).

Authors such as Tobin Siebers (2011) go into detail on the societal emphasis on bodily perfection, which contradicts the reality that as humans, we are feeble and finite and that most individuals will experience acute or chronic disability in their lifetime.

Relatedly, some body image research approaches the interaction of body image and dysmorphic concerns from a social-behavioral model, in which a person’s perspective is influenced by social experiences and cultural values (Tomas, 2016). As Gay Becker (1994) explores in her work on infertility, one’s concept of *self* can be disrupted by cultural constructs of continuity or normalcy. This closely ties to how disability, whether experienced acutely or chronically, can interact with deep rooted sentiments of body image and satisfaction. When a physical disruption occurs, a person must construct a new context to restore a sense of coherence. This notion critically relates to the medical model in which not all conditions can be “fixed.” The curative intent and fixation perpetuates a potentially painful cycle in which reestablishing coherence can be a struggle. This process is particularly strong among individuals

experiencing acute trauma or illness that result in disability. Individuals with congenital disabilities also go through an internal process by which an identity, very much influenced by a surrounding culture, is fraught with emotions that at times are characterized by a sense of failing to live up to societal norms of the idealized life (Becker, 1994).

Other research conducted on body image and physical disability explores the psychosocial framework for visualizing the interplay of these two dynamic elements (Taleporos, 2002). Erving Goffman (1963) used this perspective in discussing the attribute of deep discretization². Stigma, succinctly described by Lerita Brown (2013), “is a response to the dilemma of difference” (Brown, 2013). Both Goffman and Brown recognize that stigma changes with context. Of the three types of stigma described in Goffman’s work, “Abominations of the Body,” best represents the sort of category of stigma faced by individuals with physical disabilities. As Goffman describes, exhibiting overt or external deformations, which include physical disability or even obesity, puts one in danger of being considered socially “abnormal” and less than human. Through normative expectations, upon which we heavily rely, first appearances allow stigma to be assigned in accordance with assumed social identities (Goffman 1963).

Cultural constructs of “normalcy” are relative and vary from society to society. With that in mind, consider the insightful comments of Ann Millet (2010) with regard to cultural expectations in the United States. The cultural demand for faultlessness creates an environment in which imperfection, deviation, and disability are seen and treated as a confrontation directed towards ancient and modern icons (Millet, 2010). Deep rooted ideals of perfection not only

² A mathematics term used to refer to the process of converting continuous features to discretized features was used by Goffman to imply the process by which humans experience societal stigma, that it is the detachment and separation that is stigmatizing (Goffman 1963).

reinforce concepts of normalcy in our society, but also set an expectation of wholeness (Millett, 2010).

If an individual was not whole, was missing both lower limbs, the individual fails not only to meet the anticipation of wholeness, but further could be perceived as “unable.” Despite the reality of their abilities and capabilities, without key visual cues of behaviors such as ambulation, the lack of this “ability” is an indicator for a judgment. With an ideological baseline in which humanness is determined by ability (Siebers, 2010), we see this idea translate into a value assessment, considering the life of this un-whole, unable individual, as compared to “whole,” “able” counterparts in the specific society (Davis, 2010).

As presented by the piece by Ann Millett-Gallant, reflecting on the powerful art of Alison Lapper, neoclassical and classical works perpetuate and “communicate philosophical and political ideals through mathematically construct[ing] aesthetics, specifically, in “whole” bodies.” This critical observation is how the definition of wholeism is operationalized. Disability essentially challenges Greek ideals and the “misrepresentation of what being human means” (Davis, 2010). Not only do PWDs fall outside norm expectations with regard to physical attributes and threats to wholeism, but other aspects of a society perpetuate an image that emphasizes disability rather than ability, and accentuates differences over similarities. The world of fashion, the apparel market, and the act of clothing consumption are no exception.

Clothing & Disability

PWDs disproportionately experience substantial challenges in finding clothing that can fulfill desired characteristics of fit, comfort, style, function, affordability, etc. (Wang, 2014; Carroll 2010; Sarcone 2017). PWDs have unique needs with regard to attributes of clothing, and

the lack of available apparel creates a barrier that ultimately impacts their health, quality of life, and engagement with society.

For example, those experiencing arthritis may have diminished hand dexterity and subsequently encounter challenges with items such as buttons or zippers. Individuals with spinal conditions and who undergo surgical treatment may experience subsequent lifestyle adaptations that impact their interaction with apparel and the ability to wear certain garments such as bras. Those with Down syndrome benefit greatly from clothing designed to their unique body shapes and proportions (Downs Design Dreams, 2017).

Further, persons with diminished sensation or thermoregulatory ability may need to rely on clothing to simply keep warm. Individuals who use wheelchairs due to paralysis must be cautious about the tightness of clothing and shoes, as well as the placement of stitching and pockets to avoid pressure sores and to maintain skin health. Restrictive clothing can also make breathing a challenge or cause pain in individuals with severe trunk curvatures. Zippers may cause injury for self-catheterizing males. And clothing that is purchased in larger sizes to accommodate physical limitations might make controlling and propelling a wheelchair either difficult or risky. Examples of this include baggy or long arm sleeves that catch in the wheels of a wheel chair or baggy pockets of athletic shorts that unsafely catch the thumbs of the person propelling their chair. People with fibromyalgia may encounter intensified body pain due to clothing design and fit.

Because appearance is a statement in social and professional environments, normative dress and attire can enhance participation and translate into greater integration with society (MacDonald, 1994a). MacDonald's work linking attire and the likelihood of being hired discovered that appropriate attire among individuals with physical disabilities was a factor upon

which hiring trends depend (MacDonald, 1994a). Physical attractiveness and appropriate attire positively correlate to higher chances of being hired when compared to less attractive and inappropriately dressed individuals of comparable “ability” (MacDonald, 1994a). And it should be emphasized that it was specifically found that clothing was the attribute upon which intelligence and competence was judged (MacDonald, 1994a).

This idea supports the notion that clothing selection and coordination among individuals with physical disabilities are controllable variables which can be utilized for self-determination and improved success upon which positive reactions in work and social situations can be elicited (MacDonald, 1994a).

Since clothing helps wearers establish identity, and since some data on PWDs indicate that disability impacts our likelihood to socialize (Sarcone, 2017) and even attend religious services, clothing consumption has been listed as a missing link to self-expression and the symbolic communication of a personal, social and cultural identity (Chang, 2014).

Furthermore, finding apparel, shoes, or accessories impacts the emotional and mental health of individuals with different physical abilities or needs. Whether it be the emotional impact of wearing “frumpy” clothes during rehabilitation post bilateral leg amputation, or the confidence that comes from looking professional at a job interview despite prominent lymphedema, clothing impacts sentiments around body image and self-esteem. In fact, clothing can also play an important role in the restoration of emotional, physical, social, and economic elements for individuals undergoing rehabilitation, as was evident in the work of MacDonald (1994a). Clothing was deemed a vital part of the rehabilitation process that emphasized the direct link between physical recovery and socialization (MacDonald, 1994a).

Adaptive Clothing

When ready-made³ clothing took over the apparel market in the early 1900s, many consumers faced challenges in finding suitable clothing, and it is no surprise that individuals with physical disabilities met frustrations with trying to fit into the conventional sizing system (Thoren, 1996). Many had to find ways to alter clothing for themselves or their children, but the burden to learn a trade or allocate financial resources to the alteration of ready-made clothing is not necessarily an interest nor feasible for all families or individuals (Thoren, 1996), especially in modern times.

In the 1950s, as occupational and physical therapists analyzed the functional aspects of dress, a movement was started that considered the unique clothing needs for PWDs (MacDonald, 1994a). Though adaptive designs were generated in those early years, they were not widely adopted in the United States due to the social, political, and economic climate (MacDonald, 1994a). That climate would eventually change with important legislation such as the Americans with Disability Act (ADA) of 1990. But despite increased numbers of PWDs in the workplace (Kaufman, 1999; Chang, 2014) post-ADA implementation, the delay and loss of momentum experienced in the apparel industry during the mid to late 1900s has resulted in little progress in the apparel field, and that is still observable in present day (Kaufman, 1999).

The research of Thoren (1996) explored the systems approach to clothing for PWDs. The findings provide quality insight into current challenges (in terms of barriers of store layout, fitting rooms and apparel options), and aptly highlight the functional and symbolic value of clothing. However, the research disappointingly segregated participants into bins of “severely disabled,” “disabled,” and “able-bodied” (Thoren, 1996). This narrow consideration for the

³ Ready-made garments are mass-produced finished textile products of the clothing industry that are not custom tailored according to measurements.

spectrum of function and health exemplifies the limitation of using a medical model, contradicts contemporary thinking of disability, and fails to respect the dynamic interaction of clothing beyond the physical (structure and function) attributes of disability.

Carroll (2007) examined the particular apparel needs of working women with diverse physical impairments, and was much more inclusive in assessing disability, taking into consideration specific abilities and limitations of movements, hand and finger dexterity, and range of motion. See Illustration 2. One major finding of this study was the reported overall dissatisfaction with available products (Carroll, 2007). The main areas and common usage problems included “donning and doffing⁴, fastening, freedom of movement, fabric, aesthetics, comfort, construction and irritating features” (Carroll, 2007). This research also cited the extensive literature dating back to the early 1960s (Behrens, 1963; Frescura, 1963), which focused on categories of disability (separated by broad characterizations of amputation, scoliosis or arthritis) and clothing needs.

One use of adaptive attire is for populations of people needing permanent or semi-permanent medical devices such as jejunostomies (more colloquially known as a “feeding tube”), tracheostomies or implanted ports for dialysis or chemotherapy (Kirk, 2010). As cited by Civitci (2004), adaptive clothing designed to accommodate these essential pieces of equipment facilitate the positive and rich attributes clothing can afford in physical and emotional ways.

Lastly, fields such as applied ergonomics and anthropometry focus their attention on the mathematical and translational ways in which garments and attire can be constructed to ease challenges typically faced by aging or impairment (Nowak, 1996). For example, computer programmers are using three-dimensional (3D) imaging to measure and predict garment fit on

⁴ The terms donning and doffing is used to refer to the practice of putting on (donning) and taking off (doffing).

different body shapes, and this technology can be used with apparel design for PWDs (Thoren, 1996). Furthermore, the application of anthropometry and ergonomics merge to inform garment construction with disability in mind, looking specifically at apparel aspects of Maximum Transverse Reach (MTR) and Maximum Sagittal Reach (MSR) (Nowak, 1996). Though these fields contribute to devising adaptive apparel, much more is needed in this realm of research as little to no attention has been given on the topic of apparel design through the improved and multi-dimensional framework of the ICF.

Conclusion

Mediated by societal ideals and concepts of normalcy, the literature reveals a complex interaction between body image and disability. However, much of this research has been conducted in disease/injury specific populations, and little has been done in body image research incorporating the ICF model. Though research dates back decades, exploring and stating the need for adaptive apparel, recent examination of this topic still uses a medical or social model to explore and investigate PWD interaction with clothing. Using the ICF model in future research will facilitate the consideration of the symbolic and functional values of clothing, the environmental barriers of clothing consumption, and the personal/internal processes surrounding body image.

PART 2: PAPER – MARGINALIZED CONSUMERS: EXPLORING CLOTHING CONSUMPTION EXPERIENCES BY PEOPLE WITH DISABILITIES

Abstract

Background: Though literature has been published since the 1960s supporting the need for adaptive apparel, today's clothing market of ready-made apparel often fails to meet the needs of people with disabilities (PWDs). Since clothing directly impacts our physical health and has been shown to influence body image, self-esteem, and opportunities, such as employment, the lack of adaptive apparel in the current clothing industry perpetuates the marginalization of PWDs. Further, contemporary research looking at the consumption of clothing by PWDs through the International Classification of Functioning, Disability and Health (ICF) framework in non-existent.

Design: Qualitative methods were used to describe the lived experiences of how individuals with disabilities experience clothing. From the consumer perspective, both functional and symbolic aspects of clothing were explored. The data were gathered through individual in-depth interviews, lasting on average 33 minutes, in which participants responded to a set of predetermined semi-structured questions. Interviews were conducted over the phone, in-person, or through web-based video and chat facilitated sessions, were audio recorded, transcribed, and analyzed for themes.

Participants: Participants were recruited from around the globe through web-based convenience sampling (n=20), were at least 18 years of age, were English speaking and identified as having at least one disability. In the end, 75% of the sample identified as female (n=15), 60% were

wheelchair users (n=12), 15% were individuals with at least one major amputation (n=3), 15% had spinal curvatures greater than 30 degrees (n=3), and 10% had medical diagnoses outside of these broad categories. Seventeen interviews were conducted with individuals residing in the USA, three in other nations (2 United Kingdom, 1 Burkina Faso). The mean age was 38 years (range 16 – 70 years).

Results: Qualitative analysis identified three major themes: 1) Participants express disappointment in the style availability, and pricing options of current adaptive attire available; 1a) Participants express disappointment in the style, availability and pricing options of current adaptive attire available; 2) In addition to disability-related needs and challenges, participants also reported clothing frustrations unrelated to attributes of their disability; 3) Clothing plays an intimate role with all three aspects of the International Classification of Functioning, Disability and Health (ICF) Model.

Conclusion: Interviews with PWDs help provide a useful framework upon which innovation in the field of apparel design can blossom. Understanding the ways in which people experience and consume their clothing through a multidimensional framework of the ICF can be used to facilitate the production of better-quality apparel products with wide appeal and potential usage by consumers of diverse abilities, including our growing aging population.

Keywords: adaptive attire, inclusive design, universal design, garment construction, apparel, disability studies, wheelchair user, scoliosis, paraplegia, quality of life

Background

PWDs want apparel products and retail environments that work for them (Carroll, 2007); however, the current industry fails to provide these basics. Because the literature reveals the important role of appearance and clothing consumption on constructs of self-esteem (Tomas, 2016; 2015), afforded opportunities, such as employment (MacDonald, 1994a; Leary 1995), health (Naomi, 1991), positive sentiments of body image (O'Bannon, 1988; Taleporos, 2002; McDermott 2015) and participation in society (MacDonald, 1994a; Baker 2006), the perpetuation of sub-par shopping environments and non-inclusive apparel products is a real concern that warrants further attention and heightened saliency. This research set out to explore the dynamic lived experiences of PWDs with regards to clothing consumption and the process by which we procure and use of clothing post purchase (Chang, 2014). Unlike prior research endeavors, this study used the rich data resulting from in-depth interviews (n=20) and utilizing the strong theoretical framework of the ICF.

Clothing

Clothing serves a multitude of functions, including, meeting legal expectations of attire in public or in work settings, protection from the elements (Civitci, 2004; Chang 2014), comfort for mobility, thermo-regulation (Karjalainen, 2007; Havenith, 2002; Parsons 2002) and independence in dressing oneself. Our attire can also symbolically serve as a canvas upon which our personality and capabilities can be displayed, as well as a venue through which we can enhance our self-esteem, (Tomas, 2016; McDermott, 2015), or convey our group affiliation (MacDonald, 1994a). As a vital part to our engagement with society, clothing can either hinder or heighten our opportunity to experience normalcy, comfort, positive emotions of self-image, and improved Quality of Life (QoL) (McDermott, 2015). Conversely, dissatisfaction and/or a

negative body image has been linked to a risk factor for psychosocial dysfunction (Taleporos, 2002; McDermott 2015) and negative attitudes towards one's own body (Heider, 2015; Taleporos, 2002). Furthermore, the act of clothing consumption can help facilitate constructs of identity (Baker, 2006; Chang, 2014) and individual agency (Baker, 2006).

Individuals with disabilities (including a wide spectrum of unique physical sizes, shapes, and with varying degrees of mobility, sensation and dexterity) generally want clothing that is functional, comfortable, affordable and stylish (Wang, 2014; Carroll, 2010). Unfortunately, meeting these criteria is a real challenge, and often people must make sacrifices in another area or attribute, or simply must avoid certain clothing (or social functions demanding a certain attire) altogether. Indirectly, or directly, each feature links back to health in some way or another.

Disability

In this research, I operationalize PWDs to include those who fall within traditional parameters of “disability” and who meet the Americans with Disability Act of 1990 (ADA) definition. As stated by the ADA, a PWD is defined as meaning “an individual with a physical or mental impairment that substantially limits one or more major life activities of such individual; a record of such an impairment; or being regarded as having such an impairment” (ADA, 1990). I also want to coin and operationalize here the concept of Marginalized Consumers (MCs), which includes additional persons who do not identify as having a disability but meet challenges with finding appropriate clothing due to physical or physiologic body differences, limitations, or conditions. This includes the growing aging population.

Despite challenges in defining and counting individuals who are PWDs, it is known that PWDs constitute a significant proportion of society. In 1994, roughly 21% of the USA,

approximately 54 million people were reported as having disabilities (Kaufman, 1999). Globally, nearly 650 million people have disabilities, ten percent of whom specifically use wheelchairs for mobility (WHO, 2010). As of 2005, more than 660,000 Americans have experienced major limb loss, which includes all foot and above or below elbow or knee amputations. (Kurichi, 2010).

Spinal deformities and major musculoskeletal conditions are other major contributors to disability on a global scale. Arising from a spectrum of etiologies, these diagnoses are significant because they are quickly becoming more common as the age of populations extends and adults begin to experience progressive disorders, often requiring interventions such as surgery (Good, 2011). Osteoarthritis, characterized by loss of joint cartilage that leads to pain and loss of function (Litwic, 2013), alone affects 9.6% of men and 18% of women aged 60 years and older; by 2020, osteoarthritis is expected to be the fourth leading cause of disability globally (Litwic, 2013).

Considering other groups that may qualify as MCs, an additional 10 million live with fibromyalgia in the USA (Queiroz, 2013), and millions more have Down syndrome. Approximately 6,000 babies are born in the United States each year with Down syndrome, equal to about 1 in every 691 live births (CDC, 2012). Currently more than 400,000 people live with Down syndrome in the United States alone (NDSS, 2012).

Additionally, it is also important to highlight that only about 15% of people who have a disability were born with their impairment, which brings to light the fact that many of us will experience acute or chronic disability at some point in our lifetime (Siebers, 2011). This fact makes the concerns of consumerism for PWDs and MCs relevant to all of us.

Furthermore, Koppers (2001) explains that PWDs, especially those with physical or more visible limitations, often experience a unique interaction with society in which they are both

invisible (relegated to the borderlands of cultural activity) and also hyper-visible in the sense that they are instantly defined and categorized by their physicality (Kuppers, 2001). Thus, individuals with physical or apparent limitations or impairment must distinctively manage and negotiate these two dimensions as they navigate through the public sphere.

The ICF Model

Created by the WHO in 2001, the ICF model combines the imperfect preceding medical and social models to construct a framework with common language and universal applicability on the topic of health and disability (WHO, 2002). The ICF model acknowledges the reality that perfect health is unrealistic; claiming such fosters an unhealthy and exclusionary dichotomous culture in which disability and health are mutually exclusive. The ICF biopsychosocial model combats such narrow consideration and provides a context through which research and analysis can be conducted with thorough appreciation for the multi-dimensional attributes of health and disability. The ICF model favors the view that health and disability constitute a dynamic continuum of human existence (WHO, 2002).

According to the ICF framework, to truly explore the multidimensionality of health and disability, one must consider tangible attributes of *structure* and *function* (essentially anatomy and physiology), critically assess components of *activity* and *participation* with society, as well as consider contextual factors, both *environmental* and *personal*. These are the core facets that make up the ICF model. Please see Illustration 1.

To conduct a quality and comprehensive assessment of how PWDs experience clothing, the ICF model was used as a guiding theoretical framework. This sets the presented research apart, as previously published research looking at the consumption of clothing by PWDs through

the ICF framework is non-existent. Because the ICF model contains facets that relate to the preceding social and medical models, we present relevant literature and findings in context with how they fit in with the ICF model.

Structure and Function

Structure and function, according to the ICF, pertain to the anatomical and the physiological aspects of our bodies (WHO, 2013). Limbs and organs constitute anatomical/structural attributes, whereas dexterity, sensation or movement are considered physiologic/functional attributes (WHO, 2013). Research using the medical model, viewing disability as an ailment needing curing, emphasizes these facet above all others (Areheart, 2008). Surgical interventions that correct a spinal curvature or rehabilitation that trains individuals to walk after lower-limb amputation may be remedial efforts centered around structure and function. The medical model historically has concentrated on fixing structural and functional components of disability as primary ways to restore health (Areheart, 2008). However, it is now better understood that medical or technological interventions, with regards to structure and/or function, may not be necessary endeavors for PWDs to obtain health and well-being. Mobility by other means, through using a wheelchair or quadrupedal, may be the primary ways in which happy, healthy, functional, able individuals get around. In the ICF model, bi-pedal ambulation is not an end goal (as it would be in a medical model); it is merely an observable reality for many of us. Means of mobility and function are viewed in context with the other facets of the ICF model.

Thoren, (1996) in her research looking at a systematic approach to clothing for PWDs, used a medical model to differentiate participants. Using a disability pyramid of three categories (severely disabled, disabled, and able-bodied), the parameters for determining which tier

participants were assigned, was purely embedded in structural and functional attributes, e.g., the use of a wheelchair, height, hand function, etc. Though some findings from her research are insightful, some are disturbingly narrow minded. Participants could only fall into one of two categories, either “disabled” or “severely disabled.” And one conclusion indicated that for the “severely disabled,” “symbolic values [of clothing] are to them, fairly irrelevant,” (Thoren, 1996). I feel that had this research, with a rather robust sample size (n=65), utilized a more holistic model such as the ICF, more quality findings would have resulted.

Activity and Participation

With the help of the Americans with Disability Act (ADA) of 1990, a growing number of PWDs now participate in the workplace and marketplace (Kaufman, 1999; Chang 2014). However, challenges are present in both spheres. Though as many as 78% of PWDs (age 21 - 64) were found to be employed in 1997 (McNeil, 2000), challenges still exist for PWDs as appearance has been found to be an attribute upon which hiring trends depend (MacDonald, 1994a). Further, beyond the fact that product design of apparel limits access to the experience of normalcy in dress, structural barriers in shopping venues also impact the act of engaging in the consumption of clothing by PWDs (Baker, 2006).

Opportunities Afforded

Because appearance and attire make statements in social and professional environments, normative dress and attire have been found to enhance participation in society and improve chances of opportunities, such as employment (MacDonald, 1994a). MacDonald (1994a) looked at the impact appearance had on the likelihood of being hired for a job. Her research considered

able-bodied individuals, as well as PWDs. It was found that physical attractiveness and appropriate attire positively correlate to higher chances of being hired when compared to less attractive and inappropriately dressed individuals of comparable “ability” (MacDonald, 1994a). Also, it should be highlighted that it was specifically found that *clothing* was the attribute upon which intelligence and competence was judged (MacDonald, 1994a). These findings support the notion that clothing selection and coordination among PWDs are controllable variables which can be utilized for self-determination and improved success in work and social situations, can be elicited (MacDonald, 1994a).

Shopping as Participation

The marketplace allows individuals to engage in self-construction, participate in collective interaction and achieve social integration (Baker, 2006). Because shopping and participation in the marketplace constitutes a healthy aspect of everyday life, and is considered a socially relevant norm and ritual, the persistence of architectural barriers in retail stores with limited availability of clothing that meets the needs of PWDs, diminishes the opportunity for PWDs to experience consumer normalcy (Baker, 2006).

Contextual Factors

The research around contextual factors for clothing consumption by PWDs is robust, and describes how elements of culture, historical legislation, and important issues of identity and body image relate with one another.

Environmental

Not only do PWDs disproportionately experience more challenges in finding clothing that can fulfill desired characteristics of fit, comfort, style, function, and affordability (Wang 2014; Carroll, 2010), retail environments often fail to meet the standard of accessibility the ADA calls for (Kaufman, 1999). This may be largely due to the fact that PWDs have historically been left off the radar of market research (Chang, 2014).

Apparel Products

In the 1950s, as occupational and physical therapists analyzed the functional aspects of dress, a movement was started that considered the unique clothing needs for PWDs (MacDonald, 1994a). And though adaptive designs were generated in those early years, they were not widely adopted in the United States due to the social, political, and economic climate (MacDonald, 1994a). That climate would eventually change with important legislation such as the ADA of 1990. But despite increased numbers of PWDs in the workplace post-ADA implementation (Kaufman, 1999; Chang, 2014), the delay and loss of momentum experienced in the apparel industry during the mid-to-late 1900s has resulted in little progress in the apparel field that is still observable in present day (Kaufman, 1999).

Individuals with disabilities generally want clothing that is functional, comfortable, affordable and stylish (Wang, 2014). However, as acknowledged by Thoren (1996) in her research on clothing for PWDs, the quality of clothing as experienced by PWDs is essentially *poor*, as it does not meet the standards set forth by the International Organisation for Standardisation (ISO). The ISO definition of quality, as experienced by the user reads, “All the properties of the product put together, which enables it to fulfill expressed and implicit needs” (Thoren, 1996).

When ready-made clothing took over the apparel market, many consumers met challenges in finding suitable clothing, and it is no surprise that individuals with physical disabilities met frustrations with trying to fit into the conventional sizing system (Thoren, 1996). First and foremost, not all sizes are sold on the clothing market (Thoren, 1996). Consequently, many must find ways to alter clothing for themselves or their children, but the burden to learn a trade or allocate financial resources to the alteration of ready-made clothing is not an interest nor feasible for all families or individuals (Thoren, 1996).

Fortunately, in the form of generating adaptive apparel or clothing products using universal design concepts, there has been a recent effort to learn the dimensions of clothing purchase selection, consumption, and satisfaction in a more inclusive approach (Chang, 2014).

Retail Architecture

In addition to apparel challenges, structural barriers, in the form of transportation, retail accessibility and fitting-room accommodations, also present difficulties for PWDs in the realm of clothing consumption.

With regard to ADA regulations, there seems to have been more emphasis on the workplace, and thus uneven understanding of how the ADA regulation applies to the marketplace. The legislation hints at “reasonable access,” which often translates into architectural changes (ramps, wider doors, bathrooms etc.). But not only are store-specific accessibility information or regulations on architecture or layout not widely available, making the experience of shopping a challenge for those with disabilities, major limitations have been observed in the enforcement and specificity of what accommodations are to be expected and made within retail (Kaufman, 1999).

Further, this is a hard challenge to overcome as the concerns of store owners are valid for reasons such as there may be considerable expenses associated with major mandated changes, and this won't necessarily translate into increased numbers of customers; in fact, it may negatively impact shelf space (Kaufman, 1999).

Market Research

Throughout history PWDs have been invisible, ostracized and devalued in a multitude of settings and through a myriad of actions, policies, and social neglect. This neglect also applies to consumer market research, resulting in a lack of understanding of shoppers with disabilities, and MCs, as they relate to dress (Chang, 2014). As presented by Chang (2014) in her qualitative research on clothing selection by female college students with disabilities, not only must we recognize a marginalized population when constructing our markets and commodities; we must acknowledge that clothing selection “is an important means by which individuals achieve emotional and psychosocial satisfaction and express their personal and social identities” (Chang, 2014).

Personal

The personal aspect of the ICF model encompasses a myriad of attributes. Related to clothing and disability, they may include: the internalizations of concepts around identity, body image, appearance, individual agency and processing experiences of stigma and societal expectations of bodily perfection.

Body Image

Body image is a way in which individuals experience body representation, the subjective picture or mental image of one's own body (Tessari, 2010). Body image, as defined by Teal (1975) also involves feelings and attitudes towards one's own body (Taleporos, 2002). Twenty-first century literature states that body image is a construct with cognitive, behavior, and emotional elements as they relate to physical appearance (Cash, 2011; Grogan, 2006; Bailey, 2016) and body function (McDermott, 2015). Since body image has been shown to affect our emotions, thoughts, and behaviors, its role in our everyday lives and its influence on our relationships and overall quality of life should not be minimized (Tomas, 2016).

Some researchers consider that body image can be delineated into two core facets: body image *evaluation* and body image *investment* (Mancusco, 2016). The former facet focuses on the emotional element of body image in which a person's thoughts and beliefs about their physical appearance are central; for example, the level of satisfaction with one's body. The latter, through denoting the importance one places on body image as well as the actual motivation and management of their appearance, emphasizes the cognitive and behavioral elements of body image (Mancusco, 2016).

Multiple studies have revealed the intimate interaction between disability and body image *evaluation*. One particular study (Romeo, 1993) of adult men with spinal cord injuries (n=47) found a negative correlation; disability was seen to negatively impact body perception and satisfaction. Similarly, in a study of females with spinal cord injuries (Kettl, 1991), sentiments of decreased attractiveness were reported as a mediator for negative body esteem (Taleporos, 2002). Additionally, a study of 3,000 adolescents found that participants with chronic conditions had lower body image scores than their able-bodied peers (Wolman, 1994).

As for research addressing body image *investment*, one recent study looked at the issue of stigma and body image when paired with stigma of physical disability (Bailey, 2016). Using a small sample of individuals with spinal cord injuries ($n=9$), participants shared a major preoccupation with mechanisms to improve attractiveness; they shared how they used fashion, make-up and jewelry to hide or accentuate certain of their features (Bailey, 2016).

Spoiled Identity

The cultural demand for faultlessness creates an environment in which imperfection, deviation, and disability are seen, and treated, as a confrontation directed towards ancient and modern icons (Millett, 2010). Deep rooted ideals of perfection not only reinforce concepts of normalcy, but also set an expectation of wholeness (Millett, 2010).

Thus, PWDs may go through an internal process by which an identity, very much influenced by a surrounding culture, is fraught with emotions that at times are characterized by a sense of failing to live up to societal norms of the idealized life (Becker, 1994). This closely links to the concept of stigma as described by Goffman (1963) in which exhibiting overt or external deformations, which include physical disability or even obesity, puts one in danger of being considered socially “abnormal” and less than human. In fact, Goffman claims that it is *appearance* that allows stigma to be assigned in accordance to assumed social identities (Goffman, 1963).

I shop, therefore I am

Further, since clothing has been shown to be a means by which wearers establish identity, and since some data on PWDs indicate that disability impacts our likelihood to socialize and

even attend religious services, clothing consumption has been listed as a missing link to self-expression, and to the symbolic communication of a personal, social and cultural identity (Chang, 2014).

Lastly, according to Baker, the four dimensions that make up the consumer normalcy construct (I am here, I am me, I am in control and I belong) reveal how shopping experiences contribute to a sense of identity and individual agency (Baker, 2006). While individuals choose to engage in shopping for recreational or economic reasons, the symbolic values of shopping affirm one's identity and place in society (Baker, 2006). The marketplace also allows individuals to engage in self-construction, participate in collective interaction and achieve social integration (Baker, 2006).

The literature, related to disability and clothing consumption, and thoroughly vetted through the ICF framework, establishes a formative foundation upon which qualitative research can be conducted.

Statement of Purpose

This study sought to capture rich data through a qualitative strategy to construct a better understanding of the nuanced and dynamic nature in which clothing interacts with the function, participation, health, and QoL of PWDs.

Methods

Here I describe my steps in conducting the research, including: the approach, the development of the instrument utilized, methods used for sampling and recruitment, data collection, and the analytical process.

Approach & Framework

I ultimately chose to conduct one-on-one in-depth interviews as means of data collection. The qualitative strategy allowed me to reach my research objectives of discovering how individuals with disabilities think and feel about their experiences with clothing. I felt that individual interviews better suited the research than other qualitative methods, such as focus groups. Not only did interviews allow for rich data to be collected on a personal/individual level, but due to the geographic dispersion of interested participants, and restraints of time-coordination between time zones, finances, and human resources, individual interviews were most feasible to execute.

While developing the protocol, recruitment tools, and interview guide, theoretical and philosophical perspectives were examined (Solvang, 2007) through an extensive literature review to assist in developing a deeper understanding of the constructs around disability, adaptive attire and issues pertaining to body image, apparel, appearance, and normalcy. The most influential framework that would provide a conceptual guide for the coding schemes, and analytical process (Weston, 2001) was the ICF model. Strategies used to minimize threats to validity included the utilization of the Consolidated Criteria for Reporting Qualitative Research (COREQ) (Tong, 2007) and consulting the Standards for Reporting Qualitative Research (SRQR) (O'Brien, 2014).

Instrument

A semi-structured interview protocol was developed that included questions pertaining to adaptive attire, experiences obtaining clothing, limitations and challenges, as well as the impact on sense-of-self and self-confidence. I devised questions from personal experience, anecdotal

observations of PWD clothing usage in prior clinical work, consultation with professors, conversational feedback from PWDs, and the qualitative and quantitative literature that exists on the topic of adaptive clothing, ergonomic design in apparel, or clothing limitations for PWDs. The questions were designed to elicit the lived experiences of PWDs and clarify how clothing impacted their daily activities, experience of health and well-being, played a role in their self-confidence and influenced their participation in society.

The interview guide included two opening questions requesting demographic and body defining information for stratum delineation followed by five grand tour questions. Additionally, general, comprehension, recall, and specific verbal probes were documented on the interview guide and utilized to foster depth and quality responses from participants (Turner, 2010; Willis, 1999). Through cognitive testing conducted in PHP2060 in Spring 2016, comprehension, retrieval, decision process, as well as response process were assessed (Harris, 1999; Barofsky 2000). And with further ample feedback from Dr. Shield, Dean Wetle, and Sarah Skeels, three rounds of major revisions were made to the original draft and questions were reworded to facilitate the think-aloud technique. Please see Appendix 1 for the full interview guide. The full protocol for this research including all instruments, and recruitment tools received IRB approval by the Brown University's Office of Research Integrity on December 12th, 2016. Please see Appendix 2.

Sample & Recruitment

Four tactics were used for recruitment: 1) personal network, 2) social media advertising on relevant groups, 3) cold reach to graduate students via an institutional listserv at Brown University, and 4) subsequent referrals and snowball effect by participants (Babbie, 1992). A draft recruitment message template was used for consistency in soliciting participation, as well as

a recruitment flyer. And though no identifying information was collected or stored with data, I did have personal interaction with all participants through social media, email and or phone to facilitate scheduling interviews and allowing for opportunities so that participants could provide additional insight post-interview. Due to budget constraints for conducting this research and the risk of minimizing any effect of coercion for a potentially vulnerable population, no financial incentives were offered.

Eligibility to participate in the interviews met the following criteria:

- English proficiency, enough to feel comfortable conducting the interview in English;
- Access and the ability to conduct the interview via phone, skype, in-person, or text-chat-platform;
- 18 years of age
- Have a body modifier that falls into one of four major categories:
 - Currently diagnosed or have visible and significant anatomical curvature such as severe scoliosis;
 - Be a wheelchair user;
 - Has had any major amputation, includes all foot and above or below elbow or knee;
 - Self-identifies as having a condition or ailment (chronic or acute) that impacts their personal engagement with clothing consumption and use

Care takers were also eligible to interview, if they themselves were over 18 years of age and the person they were speaking on behalf of meets the above criteria.

Data Collection

Data was collected by means of audio recorded interviews. Interviews were conducted from April 2016 until January 2017. Interviews were conducted in the English language. Two separate recording devices were used for each of the interviews to safeguard against mechanical failure or sound quality concerns. Recording software and devices included: QuickTime,

Android OS audio recorder, and a handheld Samsung voice recorder application. All participants provided verbal informed consent before the audio recording was initiated. Interviews ranged between 17 and 71 minutes duration, depending on the participant. Interviews were then transcribed verbatim into a word processing document within several days of initial recording. Interview transcriptions were checked against the initial audio recordings twice – once for quality control and accuracy after initial transcription, and again while formatting the documents and to check that no identifying information was revealed on the part of the participant during the interview.

Analysis

Microsoft Word was the preferred software for initial deductive and inductive review of the transcriptions. Through implementing a hybrid approach of conventional and summative content analysis (Neale, 2015; Hsiu, 2005), a coding scheme was established. Considering the theoretical framework of the ICF model, initial coding ideas were delineated by color to accommodate the categories of the ICF model, which fostered a better analytical process by which I could more clearly discern which aspects of individuals' lives were impacted by aspects of clothing consumption. Thus, my three parent codes consisted of: 1) Structure and Function, 2) Activity and Participation, and 3) Contextual Factors. Codes principally originated from the content of the text data, and some transcripts required additional sub-coding, particularly when delineating positive vs. negative experiences. Interviews were then read multiple times in their entirety during the weeks following the last interview. This process facilitated the synthesis of content and meaning of interviews on an individual level and in a collective context. Through the subsequent readings, interview summaries were generated as well as compilation of general

observations. The transcripts were imported into the qualitative software package, NVivo (Version 11.1), and all transcripts were thoroughly coded. Please see Appendix 3 for the coding scheme used.

Using the analytical tools available in NVivo, major patterns of key and recurring concepts were considered for thematic significance, and representative quotes were identified to illustrate the themes. Three major themes were emerged in this round of analysis, and an additional four subthemes were also identified. An audit trail (Creswell, 2000; Cutcliffe, 2004) was maintained throughout the research to the end of analysis, and included notes pertaining to development of the interview guide, reflections on individual interviews, conceptual framing of ideas as they pertain to disability and the ICF model, thoughts and the synthesis of content learned from the literature review and relevance to the shared experiences from participants, and the emerging themes.

Results

Sample Characteristics

Twenty individuals participated in interviews, 75% identified as female (n=15), 60% were wheelchair users (n=12), 15% were individuals with at least one major amputation (n=3), 15% had spinal curvatures greater than 30 degrees (n=3) and 10% (n=2) had medical diagnoses outside of these broad categories. The mean age was 38 years (range 16 – 70 years). Interviews lasted on average, 33.25 minutes (range 17 – 71 minutes). Seventeen interviews were conducted with individuals residing in the USA, three in other nations (2 United Kingdom, 1 Burkina Faso). Half of the participants were recruited by means of social media, 5 via my personal network, 4 from participant referrals and snowball effect, and 1 individual was recruited through Brown

University's Graduate Listserv. Most interviews took place over the phone (n=13), five interviews were conducted through web-cam, one via a text-chat-platform, and one in person. See Table 1.

Thematic Findings

The information provided by participants is organized around major themes that emerged from close study of the data and discussion with thesis advisors, Dr. Renée Shield and Sarah Skeels, MPH. The study elicited three major themes (See Table 2): 1) Participants express disappointment in the style availability, and pricing options of current adaptive attire available; 2) In addition to disability-related needs and challenges, participants also reported clothing frustrations unrelated to attributes of their disability; 3) Clothing plays an intimate role with all three aspects of the International Classification of Functioning, Disability and Health (ICF) Model. The presented data and quotes were only edited for sake of clarity and brevity and all names have been changed and quotes are presented with aliases.

Theme 1: Participants express disappointment in the style, availability and pricing options of current adaptive attire available

From the participants' accounts it was evident that when considered or previously sought or used, adaptive apparel options were disappointing. Disappointment resulted from three main factors: price, the lack of style, and the difficulty in finding adaptive apparel. Participants mentioned disappointing experiences with adaptive apparel, as defined above. No participants reported currently using or seeking out adaptive apparel or clothing specifically designed for their disability.

Zoe (all names are pseudonyms), a community activist, thinks about footwear with her prosthetic feet in mind. She even mentions that her old shoes (prior to her recent bi lateral lower limb amputation) do not fit her prosthetic feet. The follow quote reveals additional frustration of design and style with adaptive footwear:

“They make diabetic-like shoes for people to wear, for like amputees or anybody that has any kind of muscular issue or whatever, but those are really ugly. They’re bulky and they’re ugly and they don’t go with anything, they clash with every single thing you want to wear. It doesn’t look good with anything. It’s like why would I just want those? I don’t just want those. I want to wear whatever I want to wear on my feet.”

Pertaining to the challenges in finding apparel, one participant described it as “hunting for a needle in a haystack.” Leslie experiences paralysis from the chest down due to a spinal cord injury, so she relies on a wheelchair for mobility. As shown by Leslie’s reflection on her prior use of adaptive apparel, we see similar concerns surrounding availability and that the fabric of adaptive clothing is not like typical clothing.

“I stopped because it looked like adaptive clothing. The fabric wasn’t the same as fabric of typical clothing. I did wear it for a while and, at the time I was really appreciative of it because I felt like, it was nice to have clothing that fit me appropriately. That was made for somebody sitting down instead of taking clothing and trying to find the clothing that worked. But I don’t anymore and I don’t even go looking for it anymore and I think, because it’s not out there enough. You have to go looking for it.”

Both Zoe and Leslie expose real concerns with current adaptive apparel options.

Theme 1a: Participants share that they want inclusive designs to be integrated with current clothing brands and venues

When probed about adaptive clothing, several participants shared the desire that adaptive apparel be sold alongside current brands and in typical venues and retail stores. Succinctly put by Maria,

“It shouldn't be that hard to incorporate it into the normal line of fashion, rather than having to have a separate line where your choices are going to be more limited, and your costs going to be higher.”

In commenting on the universal applicability of adaptive attire, Roberta, diagnosed with cerebral palsy and a wheelchair user, also talks about the stigma associated with disability, and the branding of adaptive attire.

“I just wish that they could make it more adaptable, more without it being labeled as "adaptive clothing." I mean, even able-bodied people probably struggle with some of these issues, so it would be useful. There's so many stigmas.”

And speaking to the role of designers and the desire for stylish apparel, for not just PWDs but the aging population, Barbara shares,

“I really wish that these designers would take into consideration people that do have disabilities and/or people that are elderly and it is harder for them to dress themselves. I just wish that the styles would be you know, in trend just like all the other stuff. I mean just because it's adaptable doesn't mean it has to be you know, not in good taste.”

The three participants who specifically spoke to the branding, styling, and incorporation of adaptive apparel speak to a significant issue of how they, as consumers with disabilities, would like to see adaptive apparel enter the retail market.

Theme 2: In additional to disability-related needs and challenges, participants also reported clothing frustrations unrelated to attributes of their disability

Though the interviews did reveal frustrations with clothing resulting from attributes or elements pertaining to disability, e.g., clothing interaction with devices such as wheelchairs, many participants reported frustrations with clothing that were not directly related to their disability, such as, height and bust size. Though characteristics, such as arm length, may directly relate to one's disability or diagnosis, as is the case of Penelope, it does not directly relate to the disability of Leslie. Regardless of the overlap of characteristics possibly resulting from a disability or not, many reported clothing complaints that are in line with possible clothing frustrations experienced by able-bodied individuals.

For example, when speaking about her online shopping experience, Pam mentions that she often needs to consider other body features more than her disability.

"I do online shopping because I happen to be good at it but mostly for me actually, the adaptive thing I need is just 'cause I have like unusually large boobs for my body type. And so I'll actually have to consider that more sometimes."

Pam also shared that because she plays tennis with her right arm and relies on it more than her left, her right shoulder is disproportionately bigger than her left. This concern was also heard from several other participants. And though propelling a wheelchair likely increases shoulder muscularity, it is not uniquely a trait of disability, nor even a specific disability. In fact, one participant, Jean, clearly says she's not sure if her shoulder size is related to her disability or if it's just her build.

"I don't know whether this is disability related or whether it is just my shoulders are big, but the shoulders in female clothing are awful for anyone who's got any sort of bicep muscles or shoulder muscles. You can't fit your arms in the sleeves and that is the most

depressing thing because I don't have very big boobs and so that means that when I have to get a jacket that fits over my shoulders and arms, it doesn't fit my torso at all. So I think that- for me -that's one of the most frustrating things. And you can kind of overcome that with things like ponchos, but they're not very flattering.”

For two other women, also both wheelchair users, finding shirts that fit them, given their stronger/muscular arms, is a real challenge.

Paula: *“Now that I think about it, I have a bigger shoulder, and strong arms, so some shirts don't fit me like they should either. But, I mean I just get a bigger size but, that's kind of different too for people that have like stronger upper bodies.”*

Maria: *“I used crutches for a number of years and then used a wheelchair that I pushed for 15 years, or so, so I developed muscles in my arms, so a blouse won't fit properly. Or a blouse that won't fit me every place else, I'm busting through on the arms almost like the Hulk.... and it is really hard because if you want to look good, you don't want to wear something that's too big just because that's the only way you can get your arms in it. You want the fit to look good. What woman does not want to look good”*

Sharing frustrations pertaining to physical body attributes that may not be related to their disability was not unique to these three participants, who were chosen for their emblematic narratives. Additional participants shared similar sentiments, revealing parallel frustrations with people without disabilities (PWoDs).

Theme 3: Clothing plays an intimate role with all three aspects of the International Classification of Functioning, Disability and Health (ICF) Model

Theme three brings to light, in narrative form, the multi-dimensionality of disability as viewed through the experience and consumption of clothing by PWDs. The eight subthemes that

support this parent theme arise for the uniquely different facets of other ICF model: 1) structure and function; 2) activity and participation; and 3) contextual factors, both environmental and personal.

Structure and Function

Within the context of clothing experiences that relate to the structure or function of PWDs, the below subthemes are insightful to the basic interactions between individuals and their clothing.

Theme 3a: Participants desire clothing that meets their functional needs

PWDs reported wanting clothing that works for them, not against them. PWDs I interviewed specifically valued functional aspects of clothing, such as warmth and protection. They also reported wanting their clothing to not cause injury, ill-health, discomfort or pain. The shared experiences largely related to structural and functional attributes of their own unique bodies. Considering the value placed on the mobility of his upper body, Brian talks about how he needs non-restrictive clothing so he can get around more easily. He goes into detail about his needs and his strategies:

“I don't like the constriction of my upper body, because when I get in and out of my car and such, I pull my wheelchair into the backseat of my car. And then I kind of pommel horse, or swing my legs up over the, the chair and into the front seat. And so I need mobility in my upper body. That's really important. I don't like winter coats or whatever, where I can't really move my arms freely. I need my range of motion in my arms, so that's why I don't buy winter coats. I'll just wear multiple layers. Like I'll wear a tank top and then a T- shirt, and then like a sweater, they're not filled with down. So I wear a lot of pullovers with zippers, and then I just wear like a scarf, and, you know, such. So range of

motion is really important to me, especially with my upper body. So I can reach. 'Cause when I'm walking on all fours, like through the snow or wherever, [like] when I get out of my car ... I do have a ramp on my house.... but um, I rarely use it. Once in a while if I go shopping and if I have a lot of stuff to bring in, I'll take my wheelchair out, and I can like bring it up the ramp and into the house, you know. But generally I just hop out of the car and walk on all fours and get in the house, and then I go about my business here."

Clyde, a scuba diving aficionado and wheelchair user, speaks to a different functional need from his clothing. Cautious of injury, zipper placement, and inseam lengths factor into his clothing selection and purchase.

"In clothing, one thing I am conscious of [is] am I going to be able to catheterize myself and if I'm not able to pull them down far enough to either to catheterize, that's something that I'd be conscious of. I would definitely take clothes back if they're going to do that. So when I'm looking at it, I have to make sure if it's a zipper, that when I pull my penis out or something I'm not going to be cutting myself on zippers or pinching the body, or cutting myself every step.

The quote below is of Carol's experience with clothing and its interaction with her body structure, which is impacted by severe scoliosis. Simply defined, scoliosis pertains to structural curvatures of the spine. However, severe scoliosis can impact important functional aspects of bodies, such as pulmonary and cardiac function, as well as mobility. And Carol reflects on the multiple factors in her clothing decisions, when considering her scoliosis,

"I just tend to go for like a one piece that is um, um very simple, like an athletic kind of suit. I bought a really pretty one actually, two years ago that looks all wrapped around and black and sort of decorative, pushes your boobs up a little bit, but I couldn't breathe. Same thing [when] I got a SPANX a few years ago, supposed to help with a dress, kind of pull everything in, and two hours later I had to take it off because I couldn't breathe, it's just too much constriction around the compressed rib cage. People talk about the rib

hump being the problem. But it's the other side where your ribcage is compressed, can often be the site of pain. It's crunched up. You know. On the right my ribs are spread apart [and] on the left they're compressed together, and I've got my heart, my stomach and diaphragm, and lungs all in that area, and if you put a bra around that or something and squeeze that even more... That's a tough pain."

The following quote aptly gets at the heart of clothing interaction with the structure and function of PWDs. Leslie does not experience typical sensation due to her spinal cord injury, so she needs to be hyper-vigilant about protecting her skin integrity, especially in areas that are sensitive or that she cannot see or feel. Succinctly put, she shares a myriad of clothing attributes that directly impact her health.

"I can't wear clothing that has zippers in the back of the pants for example- Because I don't want a pressure sore. And the fabric, I like fabric that has flexibility for my skin health- I need to be very cautious of that. I will never wear clothing that has a tight waist. If I have a tight waisted thing, my breathing is compromised.... I also dress for temperature. I don't thermo regulate because of my spinal cord injury, My body doesn't control its own temperature. So in the winter, I get very cold quickly so I wear a lot of layers. And sometimes finding clothing that can layer. Right now, it's not hard. Right now, it's really easy. Because it's in the style. But before when that wasn't, you know, it's frustrating when the fashion and what's available really doesn't fit your body."

This theme of considering the pure functional needs of clothing brings to light some basic concerns that may be difficult to conceive by individuals with little exposure to disability.

Theme 3b: Functional clothing is a mediator for autonomy

Due to dexterity limitations, apparel features such as zippers, buttons, clasps, etc. are not only met with difficulty but directly impacts autonomy. Pam, born with a short left arm, talks about how accessories challenge her ability to put items on herself.

“I just thought of something else too, as far as accessories go. I can't buy watches that have a leather buckle strap thing 'cause there's really no way for me to do that, I would have to have somebody put it on for me. And could maybe, maybe maneuver that with my toes, but I haven't found it to be worth it. Like, too much work to be worth it. So I get mostly like metal band watches. You could get like elastic ones, but I just don't like that personally. But it is possible to just get metal ones that have a hinge, and that's easy enough to do. When I look at watches and bracelets it's like, Am I gonna be able to hook this myself or not?”

Michael, a wheelchair user with hand dexterity limitations, also shares his experience choosing clothing by considering if he'll be able to manage with it on his own, and how that plays a role in his decision making process.

“When I am looking at clothing ... I'm thinking what is gonna be the easiest for me to deal with by myself. Which for me entails that I'm normally looking for something, like you said, with elastic waistband and sometimes I really like the joggers cause they got the elastic around the ankles. That way my pants aren't like getting wrapped up in my shoes or possibly in my wheels or things like that.... Because sometimes it will hinder me, like, especially if it's like, using the bathroom, or dealing with it myself, and then it would require me laying out [rather than] just being able to fix it in my chair.”

As can be seen in these quotes, autonomy is an important aspect of our daily life.

Activity and Participation

Individuals are experts of their own bodies and lived experiences. The below subthemes offer first-hand accounts of how clothing can relate to one's activity and participation in society.

Theme 3c: "Fitting in" is a major concern for PWDs

PWDs share significant memories and concern for "fitting in" having been a dominant part of their experiences, particularly when of adolescent age. One participant described her desire to fit in as being "overwhelming." Decades later, Carol shares how she can remember what it was like when she was younger and feeling left out.

"I think it's harder for adolescent girls. It's been many years for me but, I wanted to dress the way the other girls dressed, and for the most part I did. I mean I graduated high school in 1982 and there were preppy clothes that I could make work. I could wear a button-down shirt with a blazer over it. But when girls were getting fancy sweaters- I couldn't do that.... And I can, as old as I am, I can look back and remember ... Feel that I was like left out. It would be nice if there was some way that fashion right now is xyz and girls with scoliosis, here's two things you can wear, or fit into that. That you can't just go to Forever 21 or wherever your girlfriends are shopping and pick something out."

Similarly, Brian remembers what it was like as a teenager to use apparel as a means to fit in with peers.

"As a teenager it was almost traumatic, because I wanted Pumas. I grew up in the '80s. So everyone was wearing Pumas. But finding shoes was very difficult and so I wound up with a pair of which were no-name, but I chose them because at least the color and they kind of look like Keds. So, long story short, I was trying, and I remember my stepfather getting impatient with me, but I was a teenager. I was trying to fit in. I was trying to be like everyone else, to whatever degree I could."

Brian and Carol have different body types, disabilities, and experiences with clothing, yet share analogous experiences around “fitting in.” For both Carol and Brian, these memories were from decades ago, but the recall was powerful.

Theme 3d: The professional environment creates additional clothing challenges

Individuals with disabilities work and participate in society, and the workplace is an important setting in which emphasis on, and expectations of, appearance are not only sometimes built into policy, but also are felt through social pressures. Karen has scoliosis and a leg length discrepancy and describes her experience with footwear in the workplace:

“Because really what I need to be wearing is sneakers and highly built up, like very strong ankle support, like athletic-looking sneakers. And when I used to work at Cornell briefly. I remember being told by someone that I needed to wear heels so I'd be taken seriously by the people that I worked with. And that just killed me. I can't wear heels. I tried. I tried doing it and I just can't do it. And so, technically, I should be wearing sneakers all the time with a lift on them. Which you know, also stands out. I feel so conscious about that. But instead, I end up, searching and searching and searching for shoes that look appropriate for work. That can also provide the support I need. So, usually that means, they need, they need to be specially made for people like me. So it has stiffness around the ankle. And then it's better if they're laces. You can tie it really tight around your ankle. And then there also can't be a heel, which is just really hard to find for women's shoes. Like, if you look at men's shoes um, you can easily find a shoe without a heel that has laces on it that expands to me. But for women, all of the nice shoes have heels, or have wedges or have no support around the ankle. Yeah, I just, I haven't been wearing the shoes that I'm supposed to be wearing. I think that's what's impacting my health.”

Similarly, Anne has prominent lymphedema and had a negative experience during a mock interview that directly related to her disability and her appearance, specifically her footwear.

“It's mainly the shoes that are challenging. Last year I was an intern at a local hospital, about half hour away. We were doing mock interviews and I went to the mock interviews with a dress on, tights, and UGG boots. And I had asked prior, "Can I wear my UGG boots?" cuz I don't really have a whole lot of choice when it comes to shoes. I was rated on a scale of, like, one to five I think, depending on my answers. And one of the categories was appearance, and I ended up getting a lower score because of the shoes I was wearing. Even though I had explained I don't really have much choice and I even mentioned it to my job developer at the time. I don't really have much choice, so I ended up getting a lower score cuz of my appearance. Which that kind of challenging. I wanted to make a good impression, so it was really hard and you know, again, I don't have a whole lot of choice, so I don't know if they didn't understand it, or I'm not sure, but ... That was a little hard to handle.”

The experiences by these two female participants unfortunately draws attention to the challenges faced by PWDs, with apparel, in the professional sphere.

Environmental and Personal Contextual Factors

Through the lens of environmental and personal factors, the below subthemes are insightful to how PWDs experience clothing in this context. Themes 3e and 3f specifically relate to environmental factors, whereas 3g and 3h relate to personal factors.

Theme 3e: Return policies are deciding variables for PWD apparel consumption

Though return policies were mentioned in several other interviews, with a preference for more generous policies, Karen's account truly captures the careful consideration of return policies and how it certainly impacts her clothing options and consumption.

"There were a couple times that I was interested in buying a pair of shoes [online] but their return policy wouldn't allow for just a straight up return. They only allowed for exchanges. And I wasn't interested in anything else they had on their website. So I intentionally didn't buy from them. So that's definitely driven like, my choices to a small extent. Recently I bought some shoes that are winter appropriate and work appropriate. I bought them from Zappos. And you can search on Zappos by orthotic friendly. And I also have to search by like, laces or whatever. And there were like a couple of options that came up. And it just so happened that one of them, I was like, "Whoa, these actually look really nice." So, Zappos has like, an amazing return policy. So there's a range, like if I'm looking at shopping at Zappos, like I'm going to try it because I can ... I'm like, definitely going to buy it and try it out. Because I have the freedom to do that. But then you know, the other companies that like, aren't so generous with their return policy..."

Viewed as a generous feature of Zappos, Pam's experiences expose an altruistic rather than capitalistic take on return policies.

Theme 3f: PWDs do not encounter truly accessible retail environments

Though ADA legislation applies to both the workplace and marketplace, participants share experiences in which retail environments are not truly accessible. Jean uses a wheelchair and has scoliosis and cerebral palsy and talks about how she may have to try items on in the restrooms of malls, or take items home when proper changing rooms are not available in some stores.

“I do like going shopping with my friends- but then the difficulty is some shops don't have proper changing rooms – Sometimes they're downstairs, or sometimes they're too small. So it makes shopping quite difficult. So what I tend to do is either go and try it on in an adaptive toilet, or take it home and then bring it back if it doesn't fit.”

Leslie, who also uses a wheelchair, shares similar frustrations with changing rooms, but also with store layout.

“I don't really particularly like to try clothes on at the store and if I do, I'll go to Nordstrom, because Nordstrom is the most comfortable of all the department stores and all the stores to look for clothing. I've had the best luck for a room where I can try clothes on- That I can fit in. And, and isn't filled with boxes and all the other things, because even though every department store and every clothing store generally has an accessible - I don't know what you call them, stall or something. Dressing room? They usually are holding all of the other stuff. So they're not accessible, really. Once you get in them, you can't move around, if you can get in them. 'Cause there aren't a lot of people, I guess, who use wheelchairs who are shopping. So usually if I go to a department store, I'll buy it and then I'll take it home and I'll try it on at home. I think what's more frustrating though is accessing, is going to a store and, you know, is environmental and not being able to get to the clothing. It's then hung too high. Or you can't get around the turnstile, whatever you call those things, you know, where there are circles. They're in the middle. Like when it's not a comfortable shopping environment, it's really frustrating.”

These two accounts of participants encountering physical barriers in retail architecture, layout and fitting rooms/stalls point to clear environmental barriers to clothing consumption.

Theme 3g: PWDs use clothing as a major way to convey aspects of identity

PWDs shared a great deal on how their clothing helped portray their personality, individual style, or even convey their intelligence and professionalism. Brian touched on deep topics related to identity and the natural process of questioning where one fits in.

“Whatever they do, with their ensemble, it says your status in the world. We all have a conversation with “Where do I fit?” You know, “How much money do I have? Where do I fit societally, socially? What kind of statement am I making? Am I... Do I want to wear the necklaces? Do I want to get all, like ... Am I goth? What kind of statement do I want to make to the world that says, you know, “I’m feeling really emo today.” Like, how do I have a conversation with the world? We’re all looking at each other constantly. Some of us more than others, but the idea is, we’re all doing that to each other, and we’re all looking at each other, and in that view, we all affect each other. I thought about clothing as the top context but just making sure I fit in socially, I kind of want to look “normal,” quote-unquote because those of us that look so visually different, I think clothing becomes an aspect where we can mitigate that. So that’s really the only point I’m trying to say, is that we try. I can only speak for myself, but I think I historically try to make sure look like I’ve got a brain in my head.”

Focused on the professional aspect of identify and image, Maria shares how she wants to be seen as imparting knowledge, not as a PWD wearing clothes that don’t fit her well.

“I also, because I do some public speaking, want, clothes that not only fit me well, but brighten me, so, um, you know, I wear fuchsia very well, and that’s, (laughs), if I’m doing anything in public, you can almost be sure that that’s a colour that I’ll wear, because it really does make me look better. So, I struggled to find a few good finds that I feel that I can look good and present myself well when I’m doing a presentation, I don’t want people to be focused on, geez, she’s falling out of that clothes, or that’s too old for her, or too young for her, you know, it’s too bad that doesn’t fit her, but, I don’t want people seeing that, I want people seeing a professional woman, you know, imparting knowledge, and so, um, so, you, the clothes, to me, have to compliment that, and I have to work really

hard to find clothes that do that, almost as hard as I have to do on the presentation, so it is a lot more work these days.”

Similarly, Leslie talks about how she presents herself, which is important to her when she considers students and colleagues. She beautifully shares that she wants her clothing to be an extension of who she is.

“I can't say why, I just have become interested in my appearance. From a "How am I presenting myself?" To my students, to my colleagues, and, I want to look, from a clothing perspective, how do I want to look? I want to look, put together I suppose. I'm not sure; comfortable. I want to look the way I feel. And I want to present myself the way I feel about myself. So, not too young, not too old, not too hip, not too cool, not too dowdy. You know? And I want my clothes to be comfortable. Because for me if I'm comfortable in my clothes I'm more confident in my clothes... I just want my clothes to be an extension of who I am.”

Using clothing to portray concepts around identity, appearing professional in professional settings, or using clothing as means to establish group identity and show where you fit in with the world is not unique to PWDs, but these representative quotes reveal poignant insight from their point of view.

Theme 3h: Participants report a positive body image

Overall, most participants shared comments indicating they had positive constructs of body image and self-esteem. Except for one participant explicitly stating she struggles with confidence, feeling attractive, and having good body image, many explicitly stated they loved their bodies, looked sexy and had little issue leading with their personality and having lots of

confidence. Leslie encouragingly talks about how her body allows her to engage and houses her mind.

“I love my body. It allows me to engage in most of the activities that I want to engage in, and it houses my mind, which is the most important thing about people, in my opinion.”

Zoe, reflecting on her recent bi-lateral lower limb amputations, also acknowledges that though there are tough times, she’s come out of it all with confidence and a strong body-positive attitude.

“I love my life and I love myself. And my boyfriend cares about me. And I visit with people and I help them through stuff and I and I let them know that “Yeah, sometimes the hard stuff [is] goanna happen [but] doesn't mean that you give up.” And dressing well helps you get through that and to move forward in that and people need to recognize that. Like even if you're not feeling well and you look good, then that's going to eventually work on you to feel better.”

The strong sentiments of body image conveyed in these quotes, and the narrative of many other participants reveal how intimately and strongly personal contextual factors play a role in the lives of PWDs; and as Zoe describes, how looking good, and dressing well, can translate into feeling better.

Taken collectively the presented quotes expose a great deal of insight to the lived experiences of PWDs, and how their clothing interacts with diverse aspects of their everyday lives.

Discussion

Many of the findings presented corroborate previous literature. However, one vehemently disputes previous work. The most striking validation was for Carroll's work from 2007, which reported "disappointment in available adaptive apparel." Though her sample of seven working-women with disabilities differs slightly from my sample of PWDs (of individuals identifying as males and females, with no specificity of employment status), it is sad to see that satisfaction with apparel needs have seemed to not improve over the past decade. I speculate that these reported disappointments of the past is the reason participants showed little interest to consider adaptive apparel in the future. I would further claim that unless main areas of disappointment change – those being style, pricing and availability – then PWD consumption and satisfaction with adaptive apparel is unlikely to change. Secondly, as hinted at by Roberta when talking about adaptive apparel and stigma, I want to emphasize that labeling a brand as a separate product line has an "othering" affect, one that should be seriously considered when looking to approach adaptive apparel design and distribution.

And though not reported as a thematic finding, many participants shared sentiments and experiences that relate to the findings of Bailey's work from 2016, in which participants reported using clothing to cover, or detract from their disability. Bailey (2016) reported that most participants shared being preoccupied with mechanisms to improve attractiveness and used fashion, make-up and jewelry similarly to hide or accentuate certain features (Bailey, 2016). Participants in my study shared similar sentiments beyond what might be hinted at such behaviors in the presented quotes. Using brand name bags to detract from disability or simply using clothing to cover certain physical features of their disability were accounts heard by research participants in my study.

Further, Thoren (1996) explored the demand on PWDs to adapt their ready-made clothing and found that many had to find ways to alter clothing for themselves or their children. The burden, however, to learn a trade or allocate financial resources to the alteration of ready-made clothing was not an interest nor feasible for all families or individuals (Thoren, 1996). Though not extensively talked about in my findings, the narratives of participants partially corroborate Thoren's findings. Only two participants actively tailored most of their clothing on a regular basis as a means to solve the problem of fit and functionality for their bodies. For the remaining sample, almost all (except for three) explicitly stated a cost barrier for considering tailoring; several interviews reported only doing so for special occasions (e.g., getting married). However, when mentioning tailoring, many shared that they relied on family members for their sewing skills, often parents. In the 1960s, one approach to solving challenges with clothing for PWDs was offering sewing classes and specific adaptive patterns (Thoren, 1996). But I strongly feel that the basic commodity of clothing shouldn't be the responsibility of PWDs to solve and sew for themselves. Not only does this create an unfair expectation or demand on PWDs and their families, but the inability to purchase clothing that is randed and sold in current retail arenas and stores again relates to Theme 1 and the othering effect of segregating apparel.

The most noticeable finding that seems to strongly oppose previous literature is *Theme 3h*, which pertains to body image. Taleporos (2002) found that sentiments and comments of physical inadequacy and unattractiveness permeated participant's narratives and cited other works with similar findings (Cromer, 1990; Romeo, 1993; Wolman, 1994; Kettl, 1991). However, it was a remarkable observation that most participants in this study conveyed strong positive body image. Though participants may have shared moments in their lifetime when self-confidence was a challenge or acknowledged lapses in positive body image, the overall tone and

portrayal was of positive attitudes and feelings towards their body. This is a delightful discovery, though should not underpin the call for improved apparel and retail experiences for PWDs. I suspect and attribute these specific finds to the general movement seen recently in the USA of body-positivity. Media has given a voice to marginalized persons, claiming autonomy and attitudes surrounding body positivity. For example, overweight individuals, or plus size models have made their way onto TV screens as well as onto the runway. And this hasn't been a silent process. Lately, incidences of body shaming or excessively Photoshopped images have made headlines, thus, influencing smaller movements on campuses and communities. Further, women of uni- or bi-lateral mastectomies have been more vocal and visual about their bodies and the changes they've experienced as women in a society that is heavily body-image-focused. I speculate that the changing attitudes around bodies in general is changing and PWDs are embracing similar body-positive sentiments.

Limitations

Limitations with this study begin with the sampling methods used. Because recruitment involved my personal network, referrals, social media advertising and an institutional listserv, sampling bias likely resulted in missing potential PWDs who do not use social media, do not subscribe to targeted groups, are outside of my personal network, or have limited access to the internet or phone connection. Further, conducting interviews only in English limited potential participants who spoke other languages, or reside in other regions, which limits the generalizability of findings. And though the sample size afforded ample quality data, the lack of diverse representation of disabilities may impact if content saturation was truly achieved in all areas. With regards to wheelchair users, the confidence of findings is more robust, whereas input

from more amputee, scoliotic patients and individuals with other disabilities may have added additional input to the findings reported. The gender representation was also not equal and thus a limitation when considering what unique clothing needs are relevant to men with disabilities and if or how they overlap with my results. Additionally, global distribution of participants was poor as the majority reside in the United States. Brand availability and cultural constructs of normalcy and disability surely may have been influenced by geographic location. Furthermore, I was the only individual coding transcripts. Even though coding teams of multiple researchers has its own limitations and potential concerns for validity, I do feel my analytic process would have been stronger with another coder as collaborative efforts often demand more rigor (Weston, 2001). Furthermore, due to the individual nature of my project, the benefits of dialectical process and co-construction was missing. Though some participants admitted to having never thought about their personal interaction with clothing prior to the interview, there is still concern for participation bias and if participants are truly representative of the population. Moreover, the coding process did not account for weight or intensity in the speaker and this may be cause for a loss in a certain type of quality data that comes from tone, inflection, volume, etc. Lastly, recall bias was a concern for several participants who were reflecting on and sharing stories from childhood, sometimes as many as forty-plus years ago.

Conclusions

In conclusion, the ICF model facilitated a thorough and in-depth analysis of the lived experiences of PWDs and their interactions with clothing. The iterative process offers substantial and rich data pertaining to clothing consumption and the findings were robust and revealed significant considerations. I passionately feel that the information gleaned from this research

facilitates the discussion that industry and proprietary brands can, and should, initiate efforts to make clothing more adaptive as there is a real need for inclusivity. Innovative, cost-effective, and simple modifications and designs are not only feasible but are: 1) a prerequisite for societal engagement; 2) critical to the opportunity to dress the part and invest in one's body image; 3) central to participation in normalcy, and; 4) long overdue for the largest minority population in the USA.

Today's clothing market of ready-made apparel fails to meet the needs of all its consumers. In some respects, this is an understandable challenge. However, with ample research, technological advances in garment design and construction, and the mere diversity of our global population, the perpetual exclusion of adaptive apparel in the clothing market facilitates the continued marginalization of millions of consumers.

No longer confined to the "discourses of medicine, therapy and victimhood" (Kuppers, 2001), PWDs deserve fair access to clothing for both symbolic psychosocial reasons grounded in body image science and important functional values of health and safety (O'Bannon, 1988).

Furthermore, since body image is truly subjective and thus is open to change and persuasion through social influences, such as through family, peers and media (Grogan, 2006), and since stigma is also contextually based and subject to change (Goffman, 1963; Coleman, 1997), I feel confident that the integration of more inclusive, universal adaptive designs will not only facilitate equitable access to functional, comfortable, and appropriate clothing that allows individuals to convey their social and personal identity, apparel design also has the ability to make subtle but significant shifts in how we internalize normalcy, stigma and body image. Johnson (2003) actually claims that maybe clothing can be a catalyst for the cultural rights

individuals deserve, the sorts of guarantees policy cannot give; she captures the related distressing topic of equal participation in her introduction in Make Them Go Away:

“The goal is not to fixate on, over-react to or engage in stereotypes about such differences, but to take them into account and allow for reasonable accommodation for individual abilities and impairments that will permit equal participation.”

Lastly, in 1994, the United Nations (UN) put forth “Standard Rules” detailing the importance of barrier-free environments, as well as the production and distribution of assistive devices. This decree was based on the belief that mobility is seen as a precondition to enjoying human rights and a life of dignity (WHO, 2010). I do not claim or approach this research, nor accept my findings, as indication of a public health problem as imperative as some of the larger structural ones offering basic needs of individuals who are differently-abled. And I support the notion that mobility, in any form, is an integral prerequisite for a fulfilling life; however, as the globe develops and technology advances, I expect the same liberties and pleasures be afforded to all persons. I argue that problems that can be solved should be solved. And so, in firmly believing that an individual’s appearance is closely knit with feelings of self-worth, engagement with society and expression of creative intellect, I see that this topic of adaptive attire falls within the parameter of offering the opportunity for a life of dignity, and thus request that it achieve more saliency.

Recommendations

Not only have diverse fields studied the importance of body image (deVignemont, 2010), identity and concepts of normalcy to a great extent (Davis, 2010), they have also been reviewed

in scholarly literature in relation to physical disability (Taleporos, 2002; Kupperts, 2001; Ben-Tovim, 1995; Rumsey, 2004; Heider, 2015; Grogan, 2006; Adamson, 2003). The same core findings emerge: image matters in terms of perception by others (MacDonald, 1994a), conveying intelligence (Leary, 1995), opportunities afforded, and group identity (MacDonald, 1994a), emotional wellbeing and self-esteem (Tomas, 2016; McDermott 2015) and feelings of attractiveness and adequacy (Taleporos, 2002; Lamb, 2001). We also know that despite adaptive attire having been studied and written about in formal scholarly work since the 1960s, and more prolifically in the 1980s (Dallas, 1982; O'Bannon ,1988; Reich, 1980; Kaiser 1985), adaptive attire has not made a significant or long lasting presence in the marketplace or design world; despite the passing of the ADA, the shopping experience is not equitable or truly accessible (Kaufman, 1999; Thoren, 1996; MacDonald, 1994b). Specialists have looked at the clothing needs of aging populations (Civitci, 2004), people with arthritis (Dallas, 1982; Naomi 1991), individuals who are wheelchair users (Wang, 2014; Abraham 2001) due to spinal cord injuries (Fuentes, 2013; Bailey, 2016; Laleh 2015) or cerebral palsy (Taleporos, 2002), and we seem to understand, in an academic way, the psycho-social implications of dress. "It is evident that the symbolic values of clothing are just as important as the functional values" (Thoren, 1996). So where do we go from here?

Future Research

Though not elaborated in the results section, there were slight, yet noticeable, differences in responses between individuals who experienced injury/disability onset decades prior compared to individuals having experienced more recent onset of disability. And because prior literature has reported qualitative findings around "bodily acceptance over time" (Taleporos,

2002), future studies could differentiate these groups to consider what differences might present themselves related to experiences with clothing given time spent with disability.

Additionally, in recent years, there has been a surge of research and production of prosthetics being intricately and fashionably designed while also improving functionality (UNYQ, 2016). However, further research regarding use and preference for non-prosthetic solutions may be an area needing attention as all of the participants interviewed who had choice in their particular prosthetic devices (n=3 of six using prosthetic devices) mentioned higher life satisfaction and functionality without prosthetics, not to mention a much easier time finding and fitting clothing.

Furthermore, since prior studies had major limitations using samples that were disability-specific or gender-specific, future studies with larger and more diverse samples in both quantitative and qualitative endeavors, will facilitate improvement in this area of research. This was also a stated recommendation in Taleporos' research (2002) that "future studies need to be conducted with larger and more randomized samples to determine the applicability of the current findings to a more representative sample of respondents."

However, that being said, the next step in research cannot merely be the perpetuation of studying if it's a necessity, and why, but launch a movement in executing new designs and finding sustainable ways to integrate inclusive apparel designs into our marketplace. It is time to start doing. It may not entirely be appropriate to neglect the element of research as qualitative and quantitative feedback will be critical in the design process, but I feel there is ample support and literature to allow for innovation, implementation and intervention to start. Maybe an aspect of research that will need attention as companies prosper or fail, will be to understand why such

endeavors fail to make it in the marketplace.

Considerations for Adaptive Apparel

The reality that perfection, and able-bodied-ness, is a temporary state at best (Siebers, 2011), makes the obvious call for adaptive attire and improved retail environments ever more relevant to even younger able-bodied individuals. Adaptive attire is not just a dire need for PWDs, but will be of use to most of us at some point in our lives, whether we experience an injury impacting our ability to walk, or we age naturally and lose dexterity in our hands.

Adaptive apparel, when available, has often been costly and poorly designed with regards to style, and has often poorly sold side-by-side with adaptive equipment. This cannot be the approach to new efforts as this only adds to the distancing, “othering” impact of segregating people with physical differences, and simply does not embrace the reality that most of us could benefit from some level of adaptive clothing at one point or another in our life. This is why I strongly feel it should not be lumped with walkers or bed pans. Clothing should be more thoughtfully designed to be inherently more inclusive and integrated with the needs of millions of people.

Inclusive Design

When design and garment construction is done well, with intent for accommodation and with ergonomics and anthropometry in mind, we see a different flavor of apparel, a refreshing approach embraced as *inclusive design*. Essentially, *inclusive design* is a framework for developing products to satisfy multiple consumers, regardless of their physical ability (Carroll, 2007). Inclusive design has roots in *universal design*, a movement that began in the late 1980s

(Carroll, 2007). In fact, the universal design criteria, originally created by the Center for Universal Design at North Carolina State University (1997), has been adapted for apparel and should be considered when approaching the topic of garment construction for PWDs or other MCs. See Illustration 3. I argue and recommend here that the inclusion of universal and inclusive design can be a strategy for future adaptive product development.

Aging Populations

Though the eligibility criterion and the sample population for the qualitative research presented here did not center on geriatric consumers, I would be amiss if I did not consider the unique clothing needs of our growing aging population. Considering that core elements of my research pertain to elements of function, mobility, ergonomics, and autonomy through the development of more appropriate clothing design for significant proportions of citizens often marginalized, it comes as no surprise that similar to young adult wheelchair users, *the current apparel market and non-inclusive designs also fail to meet the needs of the growing aging population*. Aging, a natural process, cause changes in a person's physiologic, pathologic, psychological, and social experiences, all of which impact clothing requirements (Civitci, 2004).

Lee (1997) examined consumption patterns in the life-cycle and highlighted key facts that support the revamping of the fashion industry strategy on market and apparel design to consider the aging population. These factors include: 1) the elderly population is increasing at an impressive and un-ignorable rate that can not be ignored; 2) the overall income of elderly also continues to rise, providing additional means to participate in the marketplace to purchase goods and services; 3) research indicates that though dissatisfied with the options available, the elderly

maintain interest in apparel. These facts contrast with the previously held notion and life-cycle consumption model that expects “decreased in apparel expenditure with age.”

Additional Recommendations

In order for future apparel endeavors to approach the topic of clothing production for PWDs and MCs, several quality resources exist that can facilitate better quality product development, with potentially better chances for success. Previous research calls for a hybrid mindset understanding entrepreneurship, the market, universal design, disability, ergonomics and more. Thoren (1996) suggests that a systems approach is necessary stating, “Our investigation shows that the [PWDs] cannot be helped with their clothing problems unless there is a change in the entire system.” Carroll (2007) also recommends that the apparel product development process consider and attempt to blend not only the constraints imposed by the consumer, but also those imposed by the apparel industry (Carroll, 2007). She concludes that, “two major sets of constraints exist – those imposed by the consumer and those imposed by the apparel industry. For successful sell-through to consumers, the industry should seek to mesh the two sets of constraints so optimal product quality can be achieved.”

Carroll, in later work (2010) provides specific information on clothing dimensions that were used to evaluate level of difficulty for PWDs. Please see Illustration 4. I recommend that these be considered in conjunction with the findings presented in this research, as explored through the multi-dimensional framework of the ICF, and along with the Inclusive Design Criteria previously mentioned. Lastly, when examining the importance of attire, clothing purchase decision variable (CPDV) frameworks, such as the one used in the research on the role of clothing and social participation for individuals going through rehabilitation, can help

facilitate the understanding of what attributes of clothing are most challenging to individuals experiencing temporary or permanent disability (MacDonald, 1994a). In that particular study, the following eight attributes were assessed: 1) physical comfort, 2) freedom of movement, 3) price, 4) ease of dressing, 5) psychological comfort, 6) fashion, 7) care, and 8) fitting in with the group. See Illustration 5. The guidance offered by this model, as well as the aforementioned resources will facilitate better adaptive apparel products and with consideration for the contextual, symbolic and environmental aspects of dress, millions of currently marginalized consumers will begin to experience equitable access to adequate and quality clothing consumption experiences.

Table 1. Characteristics of participants in the sample (n=20).

Characteristic	Number
<i>Country of Residence</i>	
<i>USA</i>	<i>17</i>
<i>United Kingdom</i>	<i>2</i>
<i>Burkina Faso</i>	<i>1</i>
<i>Gender</i>	
<i>Female</i>	<i>15</i>
<i>Male</i>	<i>5</i>
<i>Age</i>	
<i>18-29</i>	<i>8</i>
<i>30-45</i>	<i>4</i>
<i>45+</i>	<i>8</i>
<i>Disability</i>	
<i>Wheelchair User</i>	<i>12</i>
<i>Amputee</i>	<i>3</i>
<i>Scoliosis</i>	<i>3</i>
<i>Other</i>	<i>2</i>
<i>Recruited Via</i>	
<i>Social Media</i>	<i>10</i>
<i>Personal Network</i>	<i>5</i>
<i>Referral/Snowball</i>	<i>4</i>
<i>Listserv</i>	<i>1</i>
<i>Method of Interview</i>	
<i>Phone</i>	<i>13</i>
<i>Video Chat</i>	<i>5</i>
<i>Text Chat</i>	<i>1</i>
<i>In-Person</i>	<i>1</i>

Table 2: Themes and subthemes

Theme 1: Participants express disappointment in the style, availability and pricing options of current adaptive attire available

Theme 1a: Participants share preference for inclusive designs to be integrated with current clothing brands and venues

Theme 2: In addition to disability-related needs and challenges, participants also reported clothing frustrations unrelated to attributes of their disability

Theme 3: Clothing plays an intimate role with all three aspects of the International Classification of Functioning, Disability and Health (ICF)

Structure and Function

Theme 3a: Participants desire clothing that meets their functional needs

Theme 3b: Functional clothing is a mediator for autonomy

Activity and Participation

Theme 3c: “Fitting in” is a major concern for PWDs

Theme 3d: The professional environment creates additional clothing challenges

Contextual Factors

Environmental Factors

Theme 3e: Return policies are deciding variables for PWD apparel consumption

Theme 3f: PWDs do not encounter truly accessible retail environments

Personal Factors

Theme 3g: PWDs use clothing as a major way to convey aspects of identity

Theme 3h: Participants report positive body image

Illustration 1: Interactions between the components of ICF (WHO, 2002 p. 9)

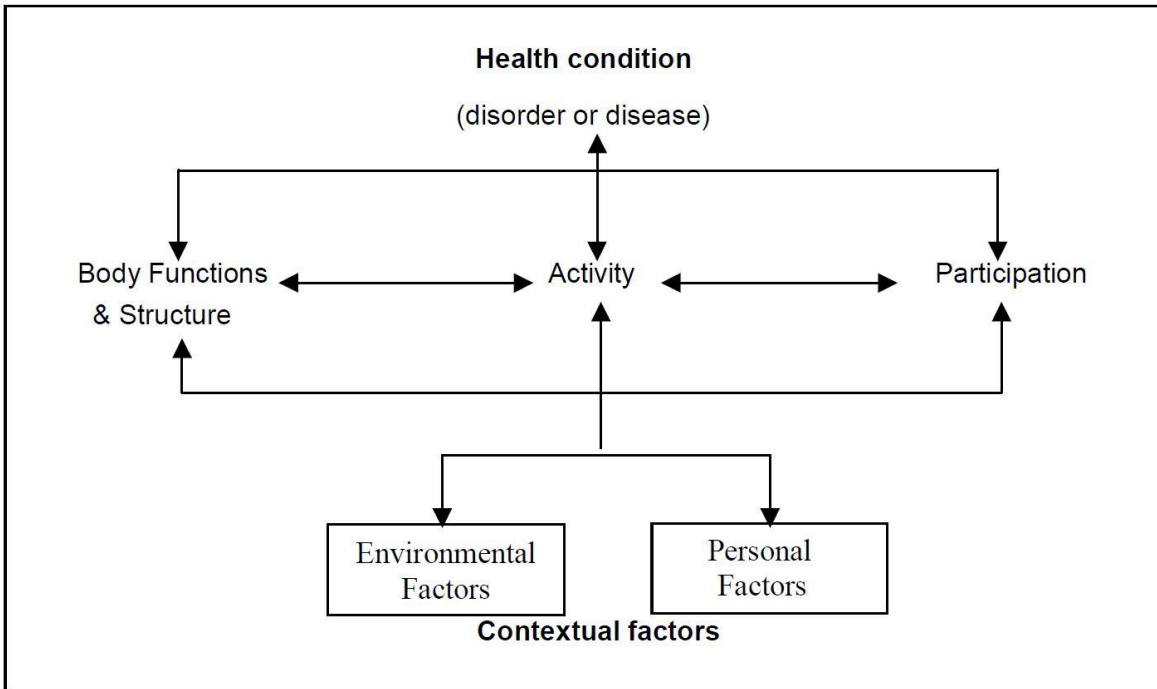


Illustration 2: The Enabler Figure (Carroll, 2007 pg. 301)

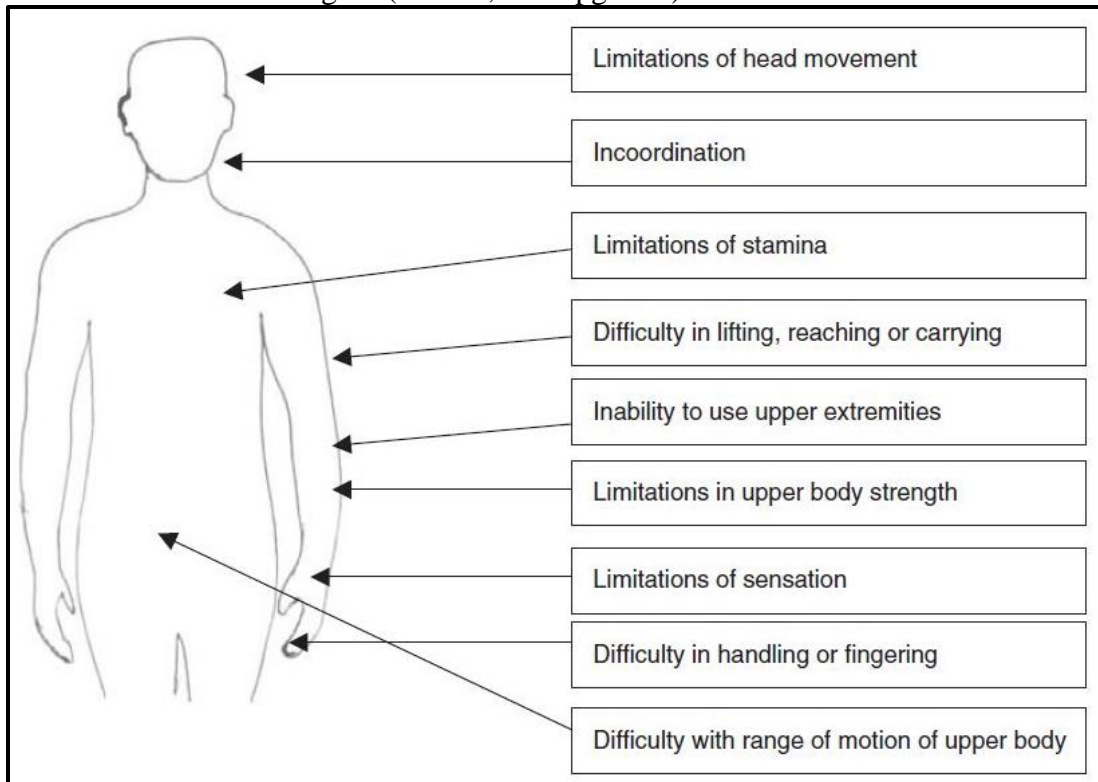


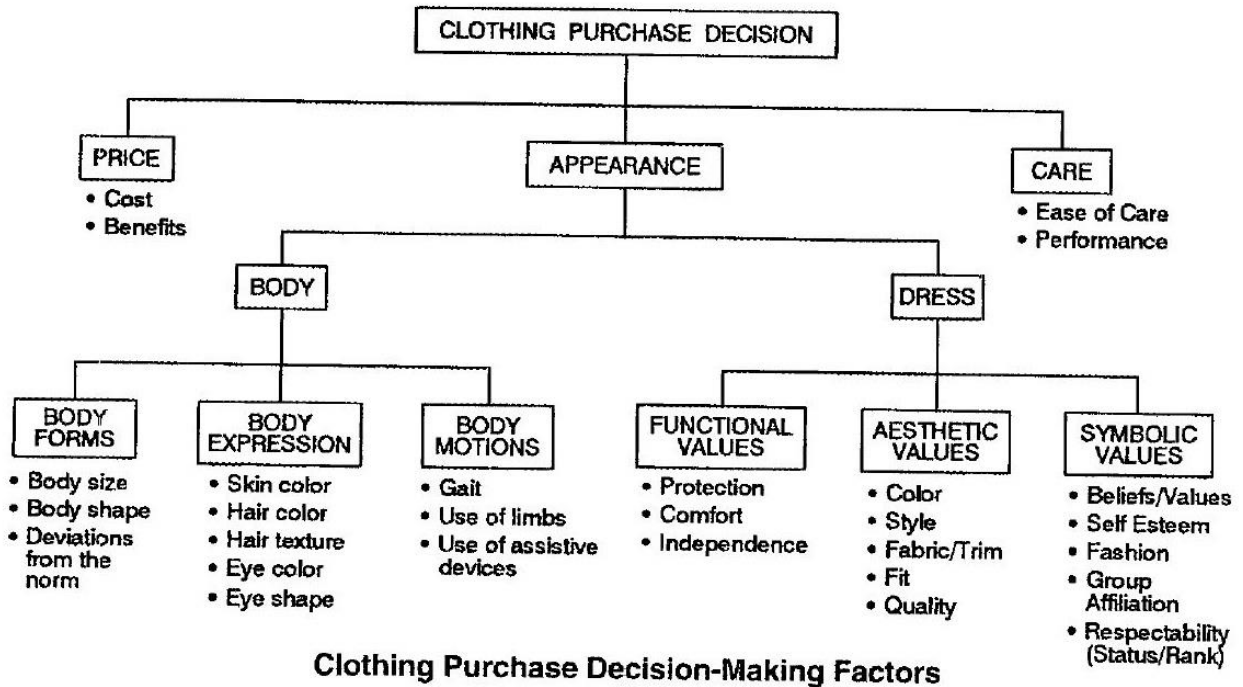
Illustration 3: Inclusive Design Criteria Adapted from Center for Universal Design (Carroll, 2007 pg. 295)

1. Equitable use: The design is useful and marketable to people with diverse abilities.
2. Flexibility in use: The design accommodates a wide range of individual preferences and abilities.
3. Simple and intuitive use: Use of the design is easy to understand, regardless of the user's experience, knowledge, language skills, or current concentration level.
4. Perceptible information: The design communicates necessary information effectively to the user, regardless of ambient conditions or the user's sensory abilities.
5. Tolerance for error: The design minimizes hazards and the adverse consequences of accidental or unintended actions.
6. Low physical effort: The design can be used efficiently and comfortably and with a minimum of fatigue.
7. Size and space for approach and use: Appropriate size and space is provided for approach, reach, manipulation, and use, regardless of user's body size, posture, or mobility.

Illustration 4: Clothing Dimensions Used to Evaluate Level of Difficulty (Carroll, 2010 pg. 9)

-
1. Donning and doffing (putting clothing on and taking it off)
 2. Managing fastenings (e.g., hooks and eyes, zippers, buttons, due to restricted use of hands and lack of mobility)
 3. Freedom of movement of clothing items (for a variety of activities, e.g., crutch walking, sitting in a wheelchair)
 4. Fabric comfort (texture and hand of fabric against the body)
 5. Fabric comfort (ability of fabric to maintain comfortable body temperature)
 6. Coverage of the body (ability of clothing to maintain desired level of modesty, e.g., while walking with crutches)
 7. Availability of desired sizes
 8. Construction quality relative to needs
 9. Extra features (e.g., embroidery, pockets)
 10. Aesthetics (attractiveness) of available clothing styles
-

Illustration 5: Clothing Purchase Decision-Making Factors (MacDonald, 1994a pg. 45)



Appendix 1: Interview Guide

Opening Questions:

Demographics-

Can state the gender with which you identify, and your current age?

Body-Strata-

Please start out by describing your body generally and say how it compares to the “typical” figure? -Is this a characteristic since birth or a recent transformation?

Grand Tour Questions:

1) Why don’t we begin with you sharing how you think about clothing?

-What feelings come up when thinking about, planning for, or wearing different styles of clothing such as casual/every day wear, cocktail party, formal occasions, business meeting etc.

-In your own words, what would you say you’re looking for in clothing? What qualities or attributes are preferred or necessary?

--What about comfort? Access? Style? Fit? Function? Ability to put on or take off?

2) Tell me how you go about getting clothing?

-Where do you do most of your clothing shopping?

--What makes online shopping easier/harder?

-You did(not) mention tailoring?

--Do you have your clothing tailored? If so, by who/where?

--What sort of additional expenses arise with needing clothing altered?

-I would love to hear more about certain brands or stores you prefer?

--What is it about that brand/store that better meets your preferences?

-Have you ever tried to look specifically for adaptive attire or any clothing made for people with similar body limitations?

--What is it about that brand/store that better meets your preferences?

3) Now I’d like to hear more about challenges you face in getting clothing.

-What frustrates you the most about clothing?

--That’s interesting.

-What do you do about those frustrations? Are there ways you avoid, minimize, or strategically deal with those frustrations?

--Can you give me an example?

-Thinking back, what is the hardest article of clothing to find that fits you the way you like?

-What’s the easiest or most satisfying article of clothing to find?

-If you could change anything about the clothing industry, what specific things would you change?

-You (haven't) brought up accessories or shoes, I'd love about your experiences with these items?

4) Fashion trends, our needs, and our tastes change over time, and I'd love to hear how your relationship with clothing has changed over your lifetime.

-When did clothing concerns begin?

-In what ways have your clothing needs changed over your lifetime?

-Thinking back, are there things that have gotten easier about finding clothing you like, that fits you well and has features that you like?

--Do you have an example?

-In what ways have you found it harder to find clothing you like, that fits you well and has the characteristics you need and want?

--Please tell me more about that.

5) Finally, could you share with me if clothing influences, or has in the past impacted, your confidence?

-In what ways do you feel that clothing adds or detracts from your persona or how you're perceived by the world?

-Describe in your own words, how clothing adds to or detracts from your persona or how you present yourself to the world.

-Is there anything about your life process and story as it relates to clothing and your confidence that you haven't shared?

Closing:

- Is there anything else you would like to share?
- Is there anything I should have asked that I didn't?

Appendix 2: IRB Approval



BROWN

Office of Research Integrity
Box 1986
Providence, RI 02912
Tel: (401) 863-3050
Fax: (401) 863-7292

Memorandum

To: Krystal Sarcone, Box G-S121-3
Renee Shield, Box G-S121-6

From: Human Research Protection Program

Date: December 12, 2016

RE: Protocol Entitled: Dressing the Part: The Role of Adaptive Attire in Differently-Abled Bodies (#1612001653).

The above referenced protocol was reviewed by the IRB under Exempt Category 2 on December 12, 2016, and determined to be exempt from the regulations of 45 CFR 46 regarding the inclusion of human participants in research.

The exemption is for three years. If your research extends beyond 12/12/2019, you will need to request another exemption one month prior to the expiration date.

If your project should change in any way which would no longer allow for a classification of 'exempt,' please contact the Office of Research Integrity, to determine the appropriate procedure for obtaining IRB review and approval. If you are unsure as to whether an amendment to your study would require IRB review, please call RPO to discuss the situation. Also, any change in the status of participants to any of the vulnerable populations (as identified in 45 CFR 46) including, pregnant women, prisoners, or those with diminished capacity, requires IRB review and approval prior to their continuing in the study.

The IRB anticipates that investigators will employ recruitment procedures that allow for the equitable recruitment of women and minorities into research studies.

Note: All research staff must successfully complete the Brown University Education Program in the Protection of Human Research Participants (CITI) at <http://www.citiprogram.org> prior to beginning work on the project.

*** For Your Information ***

The next deadline for submission of new protocols, amendments to protocols, and annual progress reports requiring full board review is January 03, 2017.

Appendix 3: Coding Scheme

Body Structure & Function	Activity & Participation	Contextual Factors
Desired attributes of clothing in relation to function and structure, e.g. ease of putting on and taking off, body temp regulation, safe to use (not catching on device etc.)	Community Engagement	Desired Attributes of Clothing (looks good, has style, conveys personality, conveys normalcy, redirects attention away from device and/or body, quality, desire to cover body)
		Positive Experiences Shopping (online or in-store) e.g. good accessibility
		Negative Experiences Shopping (e.g. physical barriers)
Spectrum of structure and function impacting interaction with clothing (levels of dexterity, mobility, sensation etc.)	Positive Experiences Shopping (online or in-store) participation with society, friends, family	Positive interactions with clothing e.g. good fit
		Frustrations with Clothing (time, cost, fit etc.)
	Negative Experiences Shopping (online or in-store) Includes time burden/additional time needed for clothing consumption, labor intense participation	Conveying of Normalcy
		Adaptive Attire (current or history of knowledge and/or use or non-use)
Body Image Reflections in Physical/Structural Sense	Positive interactions with clothing (meets their needs for things like workplace, school)	Interpersonal Encounters
		Strategies for dealing with clothing (sticking to same brand)
		Confidence / Self-Esteem
Strategies for dealing with clothing (sizes)	Frustrations with Clothing (impact on activity and participation: clothing interaction with devices)	Comments on Identity
		Specific Brands
	Strategies for dealing with clothing (avoidance)	Changes in Fashion (and resultant impact on consumption and use of clothing)
		Tailoring
		Clothing & Rehabilitation

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