FUNCTION MATTERS: EXAMINING BODY FUNCTIONALITY AS A DIMENSION OF BODY IMAGE AMONG WOMEN WITH AND WITHOUT DISABILITIES

by

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ABSTRACT

ERIN VINOSKI THOMAS. Function matters: Examining body functionality as a dimension of body image among women with and without disabilities (Under the direction of DR. JAN WARREN-FINDLOW).

Body image is defined as the thoughts, feelings, and perceptions a person has about their body. Body image disturbance is an increasingly important public health issue due to its documented associations with maladaptive health behaviors and diminished health outcomes. Emerging scholarship suggests focusing on body functionality (i.e., what the body can do) over appearance (i.e., how the body looks) may promote positive body image outcomes among women. However, this research is underdeveloped in considering the perspectives of women with disabilities, who experience profound health disparities and may be at heightened risk for body image disturbance due to differences in appearance and body function. To address this gap, I used a multi-phase, mixed-method approach to explore and measure aspects of body functionality as a component of body image among women with and without disabilities. In Phase I, women with visible physical disabilities (N = 15) participated in semi-structured interviews about body image and body functionality, aligned with a constructivist grounded theory approach. Phase I findings revealed a new construct, functional-aesthetic body image (FABI), and data were used to generate items for a FABI measurement scale. In Phase II, subject matter experts (SMEs; N = 6) reviewed the face validity of scale items. Items were revised in accordance with SME feedback. Community women with (n = 18) and without (n = 15)disabilities reviewed items for content consensus via a Delphi approach, demonstrating proof-of-concept for an application of universal design in measurement research. In

Phase III, the scale was pilot tested with a national sample of women with and without disabilities (N = 285). Exploratory factor analysis revealed 22 items loading on a four-factor structure. Item analyses, bivariate correlations, and hierarchical regression models were computed to assess the scale's internal consistency and convergent, discriminant, and incremental validity. The FABI scale was ultimately found to be a psychometrically sound and valid instrument for measuring functional-aesthetic body image among women with and without disabilities. This research makes novel contributions to the fields of body image and disability by illuminating new relationships between appearance and body functionality constructs. It also provides a methodological framework, Universal Design for Measurement, to support the inclusion and centering of people with disabilities within mainstream health and measurement research.

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CHAPTER 1: INTRODUCTION

Body image is a multi-dimensional construct defined as the cognitions, emotions, and perceptions a person has about their own body and the behaviors in which one engages to reflect those thoughts and feelings (Cash, 1990). Over 60% of US adult women and at least 40% of US adult men report poor body image, and these rates remain stable across the life course (Fiske, Fallon, Blissmer, & Redding, 2014; Tiggemann, 2004). Body image disturbance is gaining attention as an important public health issue due to its high prevalence and established associations with mental health conditions such as eating disorders and depression (Paxton, Neumark-Sztainer, Hannan, & Eisenberg, 2006; Stice & Shaw, 2002), as well as behavioral risk factors for chronic disease, including reduced physical activity (Grogan, 2006) and tobacco use (Robinson, Webb, & Butler-Ajibade, 2012).

To date, the majority of body image research predominately focuses on the experiences of among college-aged and adolescent White women and girls (Grogan, 2008; Alleva, Martijn, Jansen, & Nederkoorn, 2014). Studies examining various dimensions of body image across the life span and among women of color and diverse national origin are increasing; however, little research has explored aspects of body image among other groups, such as women with disabilities (Bailey, Gammage, van Ingen, & Ditor, 2015; Thompson, Heinberg, Altabe, & Tantleff-Dunn, 1999). This research explores body image, with an emphasis on body functionality, among women with and without disabilities.

Disability: Definitions, Guiding Theory, and Health Inequities

Disability refers to congenital or acquired structural impairments, activity limitations, or participation restrictions that reflect the complex interaction between a person's body and the society in which they live (World Health Organization [WHO], 2001). The term *disability* encompasses many conditions, including physical or mobility disabilities, cognitive disabilities, vision, hearing and other sensory disabilities, developmental disabilities, and other conditions such as chronic medical or mental health conditions that influence limitations in self-care and/or independent living. Disabilities can be visible (i.e., observable or perceivable to others) or invisible (i.e., not immediately apparent to others), and congenital (i.e., present from birth) or acquired (i.e., sustained via injury, such as a traumatic brain injury, health condition, such as limb loss due to diabetes, or as a result of aging). Approximately 25% of US adults have some type of disability (Okoro, Hollis, Cyrus, & Griffin-Blake, 2018).

Disability theory. The contemporary definition of disability has evolved in step with guiding theoretical models of disability. For example, the medical model of disability, which focuses on structural body differences and emphasizes limitations in personal capability, guided health research and service provision throughout much of the mid-20th century (Donoghue, 2003). As such, the prominent definitions of disability that informed research during that time emphasized personal limitations and focused on curing or reducing the disability (Goering, 2015).

The social model of disability. Scholars moved toward a social model of disability in the 1980s and 1990s, prompted in part by the disability rights movement of the 1970s and beyond (Beaudry, 2016). The social model presents disability as a social

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construct rising from dominant sociocultural attitudes about disability, and the resulting oppression of people with disabilities, rather than a result of individual "limitations" (Finkelstein, 1980; Oliver, 1990). As the social model gained recognition, the accepted definition of disability also evolved to include discussion of the interactions between a person with a disability and the world, predominately designed for the abled body, in which they live (WHO, 2001).

Feminist disability theory. In general, feminist theories support attempts to explain the constitution of gender, and gender inequalities and disparities. Through its long theoretical evolution, contemporary feminist theory has come to be intersectional in that it explores not only gender, but how multiple characteristics or identities such as race, sexual orientation, and class, interact with gender to further explain various levels of inequality and disparity. There are numerous domains encompassed by feminist theories; the proposed research concerns the domains of the body, representation, and identity (Garland-Thomson, 2002).

From the feminist perspective, women's body image is viewed as a result of the complex relationship between society and the gendered body, rather than a function of individual pathology. Similarly, the social model of disability contends that disability is more the function of a narrow sociocultural interpretation of human variation, rather than individual deficits or limitations (Barnes, 1991). Feminist disability theory, then, has been proposed as a framework to describe and analyze social systems and practices that stigmatize certain types of bodies (fat bodies, Black bodies, disabled bodies, etc.) that deviate from social norms or ideals (Garland-Thomson, 2002). This theoretical fusion of disability and feminist theories emphasizes the importance of considering (dis)ability as

another characteristic or identity in addition to race, ethnicity, sexual orientation, gender identity, age, etc. with which women, specifically, identify that may particularly impact how society responds to, and women themselves perceive and think about their bodies within the context of social ideals.

Universal design. Universal design is another disability-related framework guiding the present research. The universal design framework guides the creation of structures, environments, and products in a way that maximizes their utility by all people and reduces or removes the need for adaptation, modification, or specialized design (Center for Universal Design, 1997), thereby eliminating barriers considered by the social model to produce disability. The framework is rooted in the field of architecture and has been applied within education systems to maximize outcomes for students with disabilities (Bowe, 2000; Mole, 2012) and within research to guide the successful recruitment and retention of participants with disabilities (Williams & Moore, 2011).

Disability health disparities. People with disabilities experience poorer outcomes across almost all health indicators compared to those without disabilities (Altman & Bernstein, 2008). Some of the causes of poorer health outcomes among people with disabilities are attributable to the person's primary disability itself; however, in line with the social model, the widespread discrimination and exclusion of individuals with disabilities, particularly within health care systems, also influences these disparities (Krahn, Klein Walker, & Correa-de-Araujo, 2015).

The percentage of people with disabilities who delay accessing health care due to cost is more than double that of people without disabilities (27.0% vs. 12.1%; Krahn et al., 2015). People with disabilities engage in lower rates of preventive health behaviors

such as leisure-time physical activity (45.8% vs. 67.8%), and higher rates of risky health behaviors such as smoking (18.8% vs. 18.0%; Krahn et al., 2015). The incidence of diabetes and prevalence of heart disease among people with disabilities are both roughly three times higher than the incidence and the prevalence rates for people with no disabilities (Krahn et al., 2015). Individuals with disabilities also have heightened risk for mental health concerns compared with those without disabilities, partially due to their having lower rates of social and emotional support (70.0% vs. 83.1%) and experiencing significant stigma and discrimination (Chevarley et al., 2006; Krahn et al., 2015).

Women with all types of disabilities are at elevated risk for poor health. For example, they are less likely than women without disabilities to receive adequate preventive reproductive health screening (e.g., mammograms and Pap tests; Sinclair, Taft, Sloan, Stevens, & Krahn, 2014), less likely to have cancer diagnosed at early stages (Roetzheim & Chirikos, 2002), and more likely to have elevated cancer mortality (Hermon, Alberman, Beral, & Swerdlow, 2001). Women with disabilities have higher rates of depression than those with no disabilities (US Department of Health and Human Services, 2000) and may be at increased risk for eating disorders, as food restriction and purging may function as weight management techniques when engaging in physical activity is difficult due to mobility limitations and inaccessible facilities and equipment (Cicmil & Eli, 2007). Research provides evidence for a dose-response relationship in which women reporting more severe functional limitations related to their disability/ies report poorer health outcomes and behaviors (Andresen et al., 2013; Wisdom et al., 2010). Health disparities faced by women with disabilities are largely preventable (Courtney-Long et al., 2015), as they tend to stem from substantial economic and social challenges (Rimmer, Riley, Wang, Rauworth, & Jurkowski, 2004). For example, although US women saw a decline in poverty rates from 2014-2015 (from 14.7% to 13.4%), poverty rates remained the same, and disproportionately high, for women with disabilities (31.9% to 31.6%; Patrick, 2016). Women with disabilities are significantly more likely than men with disabilities and men without disabilities to live in poverty (Patrick, 2016). Reduced social support and experiences of discrimination or stigma are also significant contributors to these disparities (Nosek & Hughes, 2003).

A less often recognized factor contributing to health disparities among people with disabilities is their exclusion from mainstream health research (i.e., research not *specifically* examining issues related to disability; Office of Disease Prevention and Health Promotion, n.d.). Although activists and scholars have raised awareness about the exclusion of people with disabilities from mainstream public health research, investigators have been remiss to promote their inclusion. Many researchers lack knowledge about disability or may endorse stigmatizing attitudes about disability common in American culture, such as the belief that people with disabilities are so different from those without disabilities that they must only be studied in research that is specific to disability, rather than within mainstream studies (Williams & Moore, 2011). The field of public health retains a preventive stance toward disability and less often considers disability as an important demographic or an aspect of identity, such as race or sexual identity, which may influence health and social outcomes (Krahn & Campbell, 2011). Research recognizing disability as a sociodemographic factor or identity tends to focus solely *within* this population, for example, by using measures designed exclusively for use among persons with disabilities or tailoring interventions specifically for use in a self-contained group of individuals with disabilities. This lack of comparative research precludes the possibility of understanding and reducing disparities in the prevalence of health issues, health outcomes, adherence to interventions, etc. between people with and without disabilities.

Body Image and Disability

Given the substantial overlap between poor health outcomes related to negative body image (e.g., mental health concerns, reduced physical activity, increased tobacco use; Grogan, 2006, Paxton et al., 2006; Robinson et al., 2012; Stice & Shaw, 2002) and health disparities in these same areas faced by women with disabilities, relationships between body image and health in this population should be further explored. Indeed, women with disabilities are exposed to and expected to conform to culturally-dominant appearance expectations while simultaneously confronting the added stigma of deviating, both in terms of functionality and appearance, from the able-bodied norm (Arzy, Overney, Landis, & Blanke, 2006; Gorgey & Dudley, 2007). The combination of their heightened risk for poor body image and disparities in health and access to care may magnify this population's vulnerability to negative health outcomes.

People with *visible* physical disabilities may be particularly at risk for body image-related concerns (Perrier, Shirazipour, & Latimer-Cheung, 2015). Many changes that may occur to the appearance of the body after acquired accident or injury, or resulting from a congenital condition (such as weight gain, muscle atrophy, missing or visibly different body areas, and use of assistive devices such as wheelchairs and

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prosthetics; Gorgey & Dudley, 2007) may affect body image. People with disabilities that affect other types of functioning and may be less visible (e.g., cognitive disabilities) may also experience diminished body image, although these populations have received considerably less attention in the body image literature.

Body image among people with physical disabilities. Existing studies exploring body image among individuals with physical disabilities have used comparative (i.e., comparing dimensions of body image among those with disabilities and those without disabilities as well as comparing dimensions of body image among persons with different types of disabling conditions) and correlational (i.e., studies examining correlates of body image concerns among persons with disabilities) quantitative designs, as well as qualitative methodologies. The studies described below focused on adults and recruited female-only samples or mixed-gender samples. Given the present research, I excluded studies focusing solely on male body image from this review.

Studies comparing various body image outcomes between people with and without disabilities suggest that people with physically disabling conditions have poorer outcomes, particularly in the domains of "feeling fat" and "body disparagement" (Ben-Tovim & Walker, 1991), appearance orientation and health evaluation (Yuen & Hanson, 2002), self-perceived attractiveness, self-confidence and worries about physical deficits and sexual problems (Pfaffenberger et al., 2011). Another study compared risk factors for eating disorders, using the Eating Disorders Inventory (Garner, Olmsted, & Polivy, 1983), between women with rheumatic conditions and women with spina bifida (Gross, Ireys, & Kinsman, 2000). A higher prevalence of women with rheumatic conditions scored above the designated cutoffs for body dissatisfaction than those with spina bifida (43.5% vs. 39.6%; Gross et al., 2000). Overall, 62% of the study participants were dissatisfied with their bodies, and 8.0% of the study participants had a score in the clinically significant eating disorders range for anorexia nervosa and bulimia compared with 0.5% to 2.0% in the general population (Gross et al., 2000). Interestingly, a more recent study investigating *positive* body image (e.g., body functionality appreciation, body appreciation, and body satisfaction) among women with rheumatoid arthritis who wanted to improve their body image suggested these women experienced positive body image, and that their positive body image outcomes improved as a result of participating in an online body functionality appreciation writing task (Alleva et al., 2018). Collectively, these study findings endorse prior research conducted among people without disabilities that suggests positive and negative body image can be experienced simultaneously (Tiggemann & McCourt, 2013; Tylka & Wood-Barcalow, 2015).

Qualitative literature on body image among people with physical disabilities is somewhat limited. Themes generated from interview studies of individuals with widely varying types of physical disabilities (e.g., spinal cord injuries, osteogenesis imperfecta, Parkinson's disease, post-polio, cerebral palsy, multiple sclerosis, etc.) included internalization of negative social attitudes and increased body acceptance over time (Taleporos & McCabe, 2002); awareness of, compliance with, and reactions to body norms (Taub, Fanflik, & Mclorg 2003); appearance and disability stigma (Posen et al., 2008); appearance and weight concerns, body functionality concerns, and engagement in self-presentational behaviors (Bailey, Gammage, van Ingen, & Ditor, 2016); and body acceptance, including gratitude toward regained functionality and body appreciation (Bailey et al., 2015).

The results of these studies overall suggest that individuals with physical disabilities have higher body image concerns than the general population, and that the prevalence and degree of this concern and risk is related to other factors such as type of disabling condition (acquired vs. congenital), years since diagnosis (for acquired disability), specific diagnosis, and gender. There are several limitations to consider in this research. First, the quantitative studies have used diverse instrumentation to measure body image concerns, making comparisons across studies difficult. All but one of the quantitative studies reviewed used small sample sizes (fewer than 100 participants with disabilities), and may have been under-powered to detect effects. The quantitative studies also used non-probability sampling methods, which may have been appropriate considering the populations included; however, the field may benefit from a larger study of body image concerns within a random sample of US adults which considers disability as an identifier similar to race or ethnicity, rather than solely recruiting individuals with disabilities and matched controls. Only the two qualitative studies conducted by Bailey and colleagues (2015, 2016) and Taub et al.'s (2003) study applied and described techniques that demonstrate qualitative rigor, which raises a substantial concern about the processes by which researchers interpreted participants' experiences.

Body image among people with other types of disabilities. Limited research exists exploring body image among people with other types of disabilities, such as intellectual and developmental disabilities, which may be less visible than physical disabilities. Two studies have explored body satisfaction among individuals with intellectual disabilities who participated in Special Olympics and found that substantial proportions of athletes expressed body dissatisfaction (Pan, Maiano, & Morin, 2018; Reel, Bucciere, & SooHoo, 2013). Findings from both studies suggest those with higher body mass index were more likely to report body image concerns dissatisfaction (Pan, Maiano, & Morin, 2018; Reel, Bucciere, & SooHoo, 2013). Although autism spectrum disorders have been linked to eating disorders such as anorexia nervosa (Fonville et al., 2013) as well as higher weight (Walters, Jacquemont, Valsesia, de Smith, & Beckmann, 2010), few studies have explored body image among people with autism or other developmental disabilities. One study reported that autism-related traits predicted lower state-specific body image among a sample of college students, indicating that individuals with autism spectrum disorders may be at increased risk of negatively experiencing and appraising their bodies (Krumm, Ferraro, & Ingvalson, 2017). This research is limited in scope; additionally, no studies have explored how functional aspects related to disability (e.g., social or cognitive functioning) might influence body image among these populations.

Inclusion of people with disabilities in mainstream body image research. The precedent for including disability identifiers within federally-funded health research has only relatively recently been established with the addition of disability-related questions to most national health surveys (Krahn et al., 2015). However, it remains rare to find data concerning participants' disability status in studies outside of the field of disability research, including within the field of body image. For example, the four volumes of the journal *Body Image* published in 2018 collectively contain 75 research or editorial articles. Of these 75 articles, seven (9.3%) included the words "disability" and/or "visible difference" in the text. No manuscripts without a disability focus included information about whether people with disabilities had demographic representation in their study

samples. Although the percentage of *Body Image* manuscripts including disability terminology was much higher in 2018 than the previous year (just 2.8% of the articles addressed disability in 2017), the overall omission of disability demographic data is particularly concerning given that a majority of studies published in this field are concerned with measuring concepts that may be *directly* influenced by disability status, such as satisfaction with specific body areas (i.e., dissatisfaction with an area of the body inflicted by disability or injury, or an area of the body that has been amputated, might conceptually differ from dissatisfaction with an area of the body due to weight or shape concerns) or responses to media imagery that excludes demographically- and visuallydiverse bodies. Studies exploring relevant dimensions of body image among women with disabilities *and* mainstream body image studies that include women with all types of disabilities are needed.

Body Functionality as a Component of Body Image

Body image scholars have shifted focus, from emphasizing the *negative* aspects of body image (i.e., body dissatisfaction) to increasingly exploring aspects of *positive* body image, including body compassion, body appreciation and acceptance, broad conceptualizations of beauty, body functionality, and others (Tylka & Wood-Barcalow, 2015). Body functionality has been broadly defined as the processes one's body *can* engage in; spanning a range of activities from physical skills to social functioning (Abbott & Barber, 2010; Alleva et al., 2014). Research suggests women who focus on body functionality over appearance ("body-as-process" over "body-as-object"; Franzoi, 1995) may have greater body appreciation and experience reduced negative effects of viewing thin-ideal media, a primary driver for body image disturbance (Alleva et al., 2014; Alleva, Martijn, VanBreukelen, Jansen, & Karos, 2015; Alleva, Veldhuis, & Martijn, 2016). Theoretical and empirical research exploring body functionality is underdeveloped in considering the perspectives of individuals with disabilities.

Theoretical foundations supporting body functionality as a component of body image. The study of body functionality is specifically informed by objectification theory (Fredrickson & Roberts, 1997), body conceptualization theory (Franzoi, 1995), and theories of embodiment (Menzel & Levine, 2011; Piran & Teall, 2012). To explain how body functionality relates to body image and health outcomes for more diverse groups of women, including women with physical disabilities, I will consider these theories through the additional lens of feminist disability theory (Garland-Thomson, 2000).

Objectification theory. Society teaches women from a very young age, both directly through social and interpersonal interactions and indirectly through popular media, that their bodies exist primarily to be looked at, consumed, and used, or *objectified*, by others (Bartky, 1990). Frederickson and Roberts (1997) were the first to name and systematically identify the micro-level consequences of objectification, with emphasis on mental health-related consequences. Experiences of objectification, primarily through gaze or visual inspection, lead women to become complicit in their self-objectification (Frederickson & Roberts, 1997). Behaviorally, self-objectification manifests in numerous ways including constant body surveillance and engaging in comparison of one's body to others' and to the dominant cultural ideal (Augustus-Horvath & Tylka, 2009; Fairchild & Rudman, 2008; Fredrickson & Roberts, 1997). Both objectification and self-objectification are linked empirically to body shame, appearance

anxiety, and reduced awareness of internal body states (Fredrickson & Roberts, 1997). These three constructs lead to diminished mental health among women, namely eating disorders and disturbances, depression, and reduced productivity or flow due to constant monitoring of appearance (Calogero, 2012; Frederickson & Roberts, 1997).

Body conceptualization theory. Body conceptualization theory (BCT; Franzoi, 1995) stems from objectification theory and describes the two basic processes through which people evaluate and experience their bodies. According to BCT, people experience their bodies either as objects of aesthetic evaluation by the self or by others, or as dynamic processes in which functionality is considered more important than aesthetics (Franzoi, 1995). This theoretical framework supports the empirical evaluation of body image differences across gender identities (Franzoi, 1995). In line with objectification theory, BCT research suggests that women are more likely to possess a "body-as-object" perspective, whereas men predominately endorse a "body-as-process" view (e.g., Hilário, 2016; Lipowska, Lipowski, Olszewski, & Dykalska-Bieck, 2016).

Theories of embodiment. Embodiment is another important concept to consider in the context of the present research. Piran (2015) defines embodiment broadly as the ways in which the body inhabits the world. Two theoretical models, including the developmental theory of embodiment (Piran & Teall, 2012) and the Embodiment Model of Positive Body Image (Menzel & Levine, 2011) inform contemporary research on embodiment.

Five domains comprise positive embodiment: (a) connecting with one's own body in a positive manner that protects against negative bodily experiences; (b) living in the body with agency and appreciating its diverse functions; (c) engaging in self-care behaviors; (d) attending to and expressing the body's desires; and (e) considering the body a subjective, rather than objective, entity (Piran & Teall, 2012).

Menzel and Levine (2011) developed the Embodiment Model of Positive Body Image. The theory posits that embodying experiences, activities, or environments lead to increased positive body image outcomes. Positive body image then leads to reduced levels of self-objectification. Lower levels of self-objectification then lead to both improved health outcomes and reduced body dissatisfaction.

Various embodying activities have been shown to lead to positive body image outcomes; however, these activities typically emphasize physical skills (Blinde, Taub, & Han, 2001). The field must further investigate embodying activities that emphasize non-physical skills so that embodiment is not exclusive of certain groups, such as people with disabilities who do not have access (environmental, financial, or other) to modified athletics. Indeed, the developmental model of embodiment includes two domains of embodiment – mental freedom and social power – in addition to physical freedom (Piran, 2015). Exploration of activities such as creative endeavors and speaking engagements that center on embodiment and agency but do not require a mobility component is needed.

Empirical perspectives on body functionality. Franzoi and Shields (1984) published the first known body image study that included a body functionality focus, although they termed the concept "Physical Condition" and defined it as the stamina, strength, and agility of one's body. Avalos and Tylka (2006) later more broadly defined body functionality to include the internal signals and cues of the body. More recent research examining body functionality supports an even more comprehensive definition,

including the body's physical and cognitive skills, internal processes, creativity, self-care, and the ways the body can facilitate interaction and communication with others (Alleva, Tylka, & Kroon Van Diest, 2017; Alleva et al., 2014, 2015, 2016). The definitions and conceptualizations of the construct have evolved from their initial narrow focus, yet researchers have not *examined* the boundaries of the construct space or clarified the concept of body functionality within any population, which requires qualitative inquiry. Further, despite body image researchers' calls to conceptualize body functionality in a manner that is inclusive of people with all abilities (Webb, Wood-Barcalow, & Tylka, 2015), most *quantitative* research on the topic of body functionality, with the exception of one study (Alleva et al., 2018), has been conducted solely among individuals who have what might be considered "typical" functioning. This exclusion presents a gap in theoretical and empirical knowledge of the concept and its boundaries.

As an example, the Acceptance Model of Intuitive Eating asserts that attention to body functionality positively predicts body appreciation (Avalos & Tylka, 2006). A series of studies has confirmed that a focus on the body's function over its appearance would reduce attention to discrepancies between one's current appearance/body and cultural appearance/body ideals, resulting in reduced body dissatisfaction and body shame and increased body appreciation (Avalos & Tylka, 2006). However, a focus on the body's functionality for a woman with disruptions in functionality due to disability, age, or other factors might *increase* attention to the most salient discrepancies between her own appearance/body and the cultural ideal. Without attempting to understand what body functionality might mean and how it may influence overall body image among those whose bodies function physically, mentally, and socially differently from the norm, the definition of the construct is under-explicated.

Measurement of body functionality-related concepts. Several validated measures relating to body functionality exist. Within the disability and aging literature, for example, objective and psychometric measures exist such as the World Health Organization's [WHO's] Disability Assessment Schedule, which assesses functional ability across cognition, mobility, self-care, socialization, life activities, and participation domains (WHODAS 2.0; Ustün & WHO, 2010). Scales used within the field of body image measure different dimensions of body functionality, such as functionality appreciation (Alleva et al., 2017), functionality satisfaction (Abbott & Barber, 2010; Alleva et al., 2014), and internal vs. external body orientation (Avalos & Tylka, 2006; McKinley & Hyde, 1996). These measures were not previously validated among individuals with disabilities. A few functionality-related scales were developed for and validated among adolescents, who may conceptualize body functionality in different ways than adults (Homan & Tylka, 2014; Abbott & Barber, 2010). Still other studies used non-validated scales (Alleva et al., 2014; Alleva et al., 2016) or measurement instruments based on a narrow definition of functionality solely emphasizing physical ability (Alleva et al., 2015).

As interest in the concept of positive body image grows, it will be critical for researchers to have additional measures of aspects of body functionality that have undergone comprehensive and rigorous development and validation. Development *must* include exploration of the construct space among a broader range of individuals,

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particularly groups with a range of functional abilities, for the definition and any tools designed to measure the construct to be valid.

Dissertation Research

The present research addresses the gaps in theory and research on body functionality presented above by exploring and measuring domains related to body image, and specifically body functionality as a component of body image, among women with and without disabilities. I conducted a three-phase, mixed-method study with the intended outcome of developing a "universally designed" scale measuring one or more dimensions of body functionality that is valid for use with women with disabilities, however not specific to this population (i.e., can also be used among non-disabled women). The newly developed measurement instrument resulting from this research measures functional-aesthetic body image (FABI), a novel construct that emerged from the study's qualitative findings. This research informs body image theory and intervention development, and demonstrates possibilities for including more diverse groups within mainstream body image and other health research.

This dissertation follows the three-manuscript format. The three manuscripts align with the three study phases, described below. I present the manuscripts included in this dissertation as I would submit them to their intended academic journals; however, I should explicitly note that these manuscripts in their current format are the product of my work with limited input from my dissertation chair and committee members. I thus expect to revise the manuscripts prior to their submission for publication to more thoroughly incorporate the insights of all authors. I generally use the term "we" within the manuscripts to refer to the multiple authors I will eventually include on the final submissions. I generally use the term "I" in the introduction and discussion sections as these sections have only one author and will not be submitted to an academic journal.

It is also important to note that I wrote this dissertation using person-first language. I intend my use of person-first language to emphasize personhood before disability (e.g., "person with an amputation," "person with autism," etc.; Dunn & Andrews, 2015), rather than emphasizing disability labels (e.g., "autistic person," "schizophrenic," etc.). The American Psychological Association (APA) and the Centers for Disease Control and Prevention, as well as various academic journals in the fields of public health and psychology, advocate for the use of person-first language in all publications (Centers for Disease Control and Prevention, n.d.; Dunn & Andrews, 2015); in fact, the APA 6th edition publication manual (2010, p. 72) clearly instructs authors to "put the person first." However, many disability scholars assert that identity-first language allows individuals with disabilities to reclaim disability labels and emphasize their disability/ies as integral to their identity and pride (Dunn & Andrews, 2015). I use person-first language in this dissertation for consistency and to align with APA style for publication purposes; I in no way mean to insinuate that person-first language is the "correct" way to refer to this population. If an individual who participated in this study used identity-first language to refer to themselves or others, I retained their terminology.

The first manuscript, entitled, "'It's very valuable to me that I appear capable': A qualitative study exploring relationships between body functionality and appearance among women with visible physical disabilities," (Vinoski Thomas et al., 2019) presents the results of the Phase I research. Phase I consisted of qualitative interviews conducted with women with visible physical disabilities. The study addressed the following research

questions: (a) what are the relevant domains of body image among women with physical disabilities? and (b) how does body functionality contribute to the overall construct of body image among this population? The interviews focused on understanding body image as a whole and the construct of body functionality as a component of overall body image among women with visible physical disabilities, as there is no published research examining whether the construct shares the same meaning and theoretical positioning for this population as for women without disabilities. Themes emerging from the study findings contributed to the development of a more comprehensive, participant-endorsed definition of body functionality and a conceptual model describing the relationships between body functionality, appearance, and functional-aesthetic body image. Measurement of this new construct became the focus of the next phases of research.

The second manuscript, "Universal design for measurement: Centering the experiences of individuals with disabilities within scale development research," describes the results of the Phase II research. In this phase, I drew from qualitative findings and previously published scales to generate the content and items for a new measurement instrument, the Functional-Aesthetic Body Image (FABI) scale. In Phase IIa (or "Study One" as I describe it within the manuscript), 6 subject matter experts (SMEs) rated the items according to their relevance to the FABI construct to establish initial face validity. They also qualitatively commented on each item and the scale response options and instructions. In Phase IIb (referred to as "Study Two" within the manuscript), women with and without disabilities participated in a two-round online Delphi panel to establish consensus about the relevance and importance of the items. Women in this phase, who

on most of the scale items, supporting their relevance and content validity across a broad population. The manuscript presents the Universal Design for Measurement framework.

The third manuscript, "Psychometric analysis and initial validation of the Functional-Aesthetic Body Image scale," presents the results of Phase III, the scale's pilot testing and psychometric analysis, including in-depth item analysis, construct validity, and factor structure. In this phase, I recruited a diverse sample of participants from Amazon's MTurk (Lyerly & Reeve, 2015; Alleva et al., 2017) and pilot-tested the revised FABI scale. I conducted an exploratory factor analysis (EFA) to assess the scale's underlying factor structure and computed bivariate correlations and a hierarchical regression model to assess the scale's convergent, discriminant, and incremental validity. EFA resulted in a three-factor solution and further item analyses resulted in a final 22item scale. FABI correlated in expected directions with other measures of negative and positive body image and with a measure of functional ability. Hierarchical regression suggested the construct accounts for unique variance beyond that attributed to measures of function and appearance alone. The three studies together present a rigorous and comprehensive exploration of body functionality as it relates to overall body image and within a mixed-ability population.

Researcher Statement

I embody a range of personal and professional characteristics that influence my thinking on the topics of body image, body functionality, and disability. First, as a classically trained ballet dancer and athlete of non-conforming body size, I experienced body-related stigmatization for most of my adolescence and early adult years. Dancers are known to be at elevated risk for developing poor body image and eating disorders due to the harmful and pervasive messages about the importance of weight, body size, and body shape within the aesthetic performing arts (Arcellus, Witcomb, & Mitchell, 2014). I believe that focusing on my ability and functionality (e.g., musculature, flexibility, stamina, etc.) protected me from such negative psychological and health outcomes. My body size has been a barrier to my success as a dancer, and even as a dance teacher, as I have found that most types of professional dancing and teaching require a specific physique regardless of talent and ability. I do not identify as having any disabilities, but I have experienced various negative effects of living in a body that does not conform to societal expectations, perhaps influencing my thinking on the topics of body image and disability. My experiences in this realm drove me to choose another career path and continue to influence my perspectives about and professional interest in these fields.

Secondly, my work as a disability researcher and advocate prior to matriculating into my doctoral program strongly shaped my perspectives about disability and health. I support the notion that disability is a natural form of diversity. This perspective, at times, conflicts with that of the dominant public health paradigm, which often treats "disability" and "poor health" as one in the same. Disability as a form of identity, and the notion of "living well with a disability," or that a person can be healthy and experience disability, are just beginning to be embraced within small communities in the field of public health. Because I have worked, interacted, and built meaningful friendships and working relationships with people who have disabilities, I am attentive to disability not only as a diagnosis but primarily as a facet of one's identity. I strongly advocate for the necessary inclusion of people with disabilities in health research and programming.

It is important to note that I approached this research as a woman who does not identify as having disabilities. I worked from an *etic* perspective, as I am not a member of the population I worked with in the early phases of the study. However, my perspectives and experiences influenced this work in ways that contributed to the strength of the study. For example, in designing the interview guide and conducting interviews, I incorporated "disability etiquette" that I learned throughout my research and advocacy experience, which may have made qualitative research participants more comfortable communicating with me. Another example is that I revised language within one of the body image measures used in the Phase III study to align with expected preferences of the disability community. Without my previous experience as a disability researcher and advocate, the design of the later study phases may not have been as inclusive. My identity and experience may have also influenced this research in ways that detracted from the strength of the study. Research participants may have been more comfortable working with someone who has experienced disability (although participants were not explicitly informed of my disability status unless they asked). The aforementioned disability etiquette may have prevented me from asking questions that people with disabilities might consider rude or offensive to participants, but that may have uncovered richer information (e.g., asking how they acquired their injury). I reflected on my experiences during the implementation of these studies, as this process of reflection has the potential to enhance the study's rigor and contribution to the literature examining body image and disability. I include an in-depth discussion of my overall reflexive process in Chapter 5 of this dissertation.

CHAPTER 2: "IT'S VERY VALUABLE TO ME THAT I APPEAR CAPABLE": A QUALITATIVE STUDY EXPLORING RELATIONSHIPS BETWEEN BODY FUNCTIONALITY AND APPEARANCE AMONG WOMEN WITH VISIBLE PHYSICAL DISABILITIES¹

Abstract: Women who learn to focus on their body's functionality versus appearance may experience improved body image outcomes. This research is underdeveloped in considering the perspectives of women with physical disabilities (WPD), who have differences in body functionality and appearance that may influence their body image. This study aimed to understand how WPD conceptualize body image and body functionality and to clarify relationships between these constructs among this population. The lead author conducted semi-structured interviews with 15 WPD representing a range of ages (21-53 years) and disability diagnoses. The study employed a grounded theory approach, applying the constant comparative method throughout the data collection and analysis cycle. We interpreted themes and subthemes based on their emergence across and explanatory value within cases to develop a conceptual model of the findings. Four major themes emerged: meanings and definitions, body image stability, factors that influence body image, and the interaction of appearance and body functionality. A new concept, "functional-aesthetic body image," emerged describing women's perceptions about the appearance of their body when engaged in functions or activities. Results may stimulate advancements in body image theory and measurement, and guide further exploration of the complex appearance-functionality relationship and its links with holistic health outcomes.

¹ A revised version of this manuscript is published in *Body Image: An International Journal of Research*. The publisher permits authors to include their articles, in full or in part, within a thesis or dissertation.

Introduction

Although body image is an increasingly prevalent topic of study among health and psychology researchers, body image experiences of people with physical disabilities have not been fully explored in contemporary literature (Bailey, Gammage, van Ingen, & Ditor, 2015). Physical disability is defined as impairments in body structures, limitations in activities, and/or restrictions in participation that reflect the interaction between features of a person's body and features of the society in which that person lives (World Health Organization [WHO], 2001). Scholars estimate that 15% of people globally have some form of disability, with physical and mobility-related disabilities being most common in the US (Iezzoni, McCarthy, Davis, & Siebens, 2001; WHO, 2011). Physical disability is more common among women (19.2%) than men across the life span (12.0%; WHO, 2011). The prevalence of disability is expected to rise over the next several decades due to increased prevalence of chronic disease, as well as advances in medical technology and related longer life expectancy of US adults (Iezzoni, Kurtz, & Rao, 2014).

Women with physical disabilities, both acquired and congenital, may be particularly at risk for body image concerns (Arzy, Overney, Landis, & Blanke, 2006; Perrier, Shirazipour, & Latimer-Cheung, 2015; Stensman, 1989). Visible differences in the appearance of the body (e.g., visible muscle atrophy, missing or visibly different body areas and structures, and use of assistive devices such as wheelchairs and prosthetics; Gorgey & Dudley, 2007) are often inconsistent with dominant Western cultural body ideals for women, which emphasize a slender, "toned," youthful, and ultimately ablebodied aesthetic (Taub, Fanflik, & McLorg, 2003). Functional differences (e.g., differences in mobility, reproductive function, sexual function, and sensory issues) may also influence body image among this population (Nosek, Howland, Rintala, Young, & Chanpong, 2001).

Existing studies have explored body image in this population. Women with physical disabilities in prior studies represented various age groups and many disability diagnoses such as rheumatic conditions, post-polio, spina bifida, Parkinson's disease, cerebral palsy, multiple sclerosis, fibromyalgia, and spinal cord injury (Alleva et al., 2018; Bailey et al., 2015; Ben-Tovim & Walker, 1995; Caap-Ahlgren, Lannerheim, & Dehlin, 2002; Gross, Ireys, & Kinsman, 2000; Hassouneh-Philips & McNeff, 2005; Posen et al., 2000; Sands & Wettenhall, 2000; Taub et al., 2003; Trajano, Jorge, Brumini, Jones, & Natour, 2010). Quantitative studies have found that women with physical disabilities have more negative body image and higher risk for eating disorders than the general population, and that the prevalence and degree of body image concerns among this population may be related to other factors such as type of disabling condition(s) (i.e., acquired vs. congenital), time since acquiring disability, and specific diagnoses (Ben-Tovim & Walker, 1995; Gross et al., 2000; Trajano et al., 2010). Qualitative studies have drawn upon a range of philosophies and methods, such as grounded theory, phenomenology, and hermeneutic approaches, to illuminate the factors influencing body image among this population. Major themes that emerged from these studies include awareness of and compliance with body norms, and reactions to such compliance (Taub et al., 2003); the influence of appearance and disability stigma and physical symptomatology on body image (Posen et al., 2000); body image stability (Caap-Ahlgren et al., 2002); body and sexual esteem (Hassouneh-Phillips & McNeff, 2005); and aspects

of positive body image including body acceptance, body appreciation, and gratitude for functional gains (Bailey et al., 2015).

Scholars conducted most research exploring body image among women with physical disabilities prior to the field's recent shift toward exploring body functionality as a dimension of positive body image. Early conceptualizations of body functionality were narrowly focused, emphasizing physical functions such as the stamina, strength, and agility of one's body (Franzoi & Shields, 1984). Scholars recently asserted that body functionality should not be conceptualized simply as physical abilities, as this would render the construct only relevant to non-disabled persons (Webb, Wood-Barcalow, & Tylka, 2015). Thus, the research community defines body functionality as everything the body can do, encompassing the body's physicality, and cognitive skills, communicative processes, internal functions (e.g., breathing, digestion), and self-care behaviors (Alleva, Martijn, Jansen, & Nederkoorn, 2014; Alleva, Martijn, VanBreukelen, Jansen, & Karos, 2015; Alleva, Veldhuis, & Martijn, 2016; Alleva, Tylka, & Kroon Van Diest, 2017).

Franzoi's (1995) pivotal work on body conceptualization theory provided the basis for the study of body functionality. Body conceptualization theory purports that the human body can be understood and experienced either as an object to be appraised in terms of its aesthetic or appearance ("body-as-object") or as a functioning, moving, entity ("body-as-process"; Franzoi, 1995). Scholars have drawn upon body conceptualization theory to explore differences in body image outcomes among men, who scholars hypothesize to have more functionally-oriented embodiment, and women, who typically attend more to their appearance than their bodies' functionality (Franzoi, 1995). Other theoretical orientations informing the study of body functionality include objectification theory (Frederickson & Roberts, 1997; McKinley & Hyde, 1996; McKinley, 2011; Moradi & Huang, 2008; Moradi, 2010) and theories of embodiment (Menzel & Levine, 2011; Piran & Teall, 2012; Piran, 2015).

Recent research suggests that promoting a focus on body functionality over appearance may bolster positive body image effects among women (Alleva et al., 2014; Alleva et al., 2015; Stern & Engeln, 2018). As such, body functionality is currently positioned as a sub-construct of positive body image and is considered antithetical to selfobjectification and appearance surveillance (Abbott & Barber, 2010; Alleva et al., 2016; Frederickson & Roberts, 1997; McKinley & Hyde, 1996; Menzel & Levine, 2011; Piran & Teall, 2012). However, other contemporary research suggests that viewing media images of women's bodies in functionality-oriented or "body-as-process" positions resulted in *negative* body image outcomes (Mulgrew & Hennes, 2015; Mulgrew & Tiggemann, 2018). The seemingly conflicting results of these two studies may be explained by differences in the study context; for example, Alleva et al. (2014) used an internally oriented writing task (i.e., writing about one's own body), whereas Mulgrew and Hennes (2015) and Mulgrew and Tiggemann (2018) used externally oriented image exposure scenarios (i.e., viewing images of other women). Webb et al. (2015) called for a more in-depth examination of the construct of body functionality, particularly among more diverse populations including individuals with limitations in function and visible differences, to clarify its dimensions and theoretical positioning.

In this light, Alleva and colleagues (2018) adapted an existing body functionality intervention to examine whether focusing on body functionality could improve body image outcomes among women with rheumatoid arthritis, who often experience
functional limitations (e.g., pain, muscle and joint stiffness, fatigue) and/or changes in their appearance (e.g. hair loss, weight changes, swelling) related to their condition (Plach, Stevens, & Moss, 2004; Scott, 2014). Their study found that participants in the body functionality intervention group experienced improvements in body appreciation, body satisfaction, and functionality appreciation, as well as reduced depressive symptoms, compared to controls (Alleva et al., 2018). This research provides further quantitative support for the positioning of body functionality as a component of positive body image; however, women with physical disabilities may have nuanced understandings of the construct of body functionality and its relationship to overall body image that have yet to be fully explored. For example, studies exploring body functionality among women with varying types of physical disabilities, including those with congenital disabilities who may be more likely to consider their disability part of their cultural identity (Garland-Thomson, 2002), are needed. In addition, qualitative inquiry may elucidate the full construct space of body functionality, including its domains and definitions, within this population.

The objective of the present study was to understand meanings of and experiences related to body image, with a specific focus on body functionality, among women with visible physical disabilities. The study specifically aimed to (a) understand how women with a range of acquired and congenital disabilities representing diverse demographic backgrounds define and experience body image and body functionality, and (b) explore how body functionality contributes to the overall construct of body image among this population.

Method

Study Context

In addition to the theoretical underpinnings driving the research questions, the design and implementation of and context for the study was further informed by the principles of Universal Design for Research (Williams & Moore, 2011). Recognizing the significant barriers to participation in research often faced by individuals with disabilities, it was important to design and conduct a study that minimized barriers to participation in qualitative research to demonstrate proof of concept. We interacted with participants via online formats, enhanced where feasible by video technology.

Study Design

This study used a grounded theory approach (Corbin & Strauss, 1990; Glaser & Strauss, 1967). Grounded theory methodology underscores the discovery of emerging patterns from and generation of theories that are "grounded" in the data (Glaser & Strauss, 1967). The methodology emphasizes the simultaneous and iterative data collection and analysis, constant comparison at each stage of data collection and analysis, documentation of the decision-making process using memos or journals, and predominant focus on theory generation as the product. Each of these components is present in this study and described below.

We conducted semi-structured interviews via Skype, FaceTime, or phone to gather participants' perspectives. The semi-structured nature of the interview guide allowed the participants more control over the flow of their interviews and helped to ensure the participants were sharing experiences they found relevant to the concept, rather than simply answering questions predetermined by the interviewer (Patton, 2002). This approach was critical to the present study, as the interviewer was not a member of the study population and may not possess a full understanding of the phenomenon of interest.

Participants

Table 2.1 presents participant characteristics.

Pseudo-	Age	Race/	Disability	Disability	Education	Interview
nym		Ethnicity	Туре	Diagnoses*	Level	Length
June	28	White	Acquired	Spinal cord injury; chronic medical condition	Master's	40:00
Josette	29	White	Acquired	Amputee without the use of prosthesis	Master's	34:15
Kasey	48	White	Acquired	Spinal cord injury	Associate's	20:11
Emily	29	Hispanic	Acquired	Spinal cord injury	Master's	41:37
Susan	27	White	Acquired	Spinal cord injury	Some College	26:26
Kristen	40	Black/ African- America n	Acquired	Spinal cord injury; cognitive disability	Doctoral	54:58
Bobbi	36	White	Acquired and Congenital	Ehlers-Danlos Syndrome; pudendal neuralgia; cognitive disability; mental health disabilities	Some College	38:22
Sophie	21	White	Congenital	Cerebral palsy; speech-language impairment; chronic medical condition	Some College	32:02
Catherine	30	White	Congenital	Spina bifida	Master's	34:29
Tammy	27	White	Congenital	Cerebral palsy	Bachelor's	17:36
Charlotte	30	Hispanic	Congenital	Cerebral palsy	Some College	45:08
Chloe	36	South Asian	Congenital	Cerebral palsy	Master's	49:58
Grace	39	White	Congenital	Cerebral palsy; visual impairment	Bachelor's	53:12
Silver	53	White	Congenital	Cerebral palsy; learning disability	Master's	26:27
Marie	27	White	Congenital	Amputee with the use of prosthesis	Bachelor's	45:10

Table 2.1 Participant characteristics

*Information presented using the terms provided by participants to describe their condition(s)

Those eligible for the study identified as women and experienced a physical disability that was visible to others (e.g., their disability was visible, or the participant used mobility aids/adaptive devices that were visible to others at least some of the time) and affected their physical functioning or mobility. Eligible participants also lived in the US, could express themselves using standard English, and were between the ages of 18 and 55. The upper age limit of 55 was set to explore the research questions with women with disabilities that were not solely due to aging. We chose these inclusion criteria to facilitate rich discussion about body image related to both appearance-related and functionality-related aspects of body image. The sample consisted of 15 women. Other qualitative studies of body image among individuals with disabilities and older adults have achieved saturation with this sample size or less (Bailey et al., 2015; Bailey, Cline, & Gammage, 2016). We purposively sampled participants to represent the heterogeneity of the population of individuals with disabilities and allow us to access "information-rich cases" (Patton, 2002, p. 230). The final sample represented various types of disabilities (e.g., congenital and acquired, varying diagnoses) and other characteristics of identity (e.g. racial/ethnic, educational attainment).

Research Team

The study team was comprised of six researchers, including one female doctoral candidate, four female faculty members, and one male faculty member, who had collective expertise in body image, disability, public health, and health psychology. One research team member identifies as having disabilities. The lead author conducted all interactions with participants. At the time we conducted the study, the lead author was a 31-year old, White, non-disabled female doctoral candidate with training in public health

and neuroscience and six years of experience working with individuals with physical, intellectual, and developmental disabilities. She had shoulder-length blonde hair and possessed slightly larger than average body size for an American woman. When conducting interviews, the lead author was visible from the shoulders up and wore neutral clothing and minimal jewelry and makeup. She wore glasses for some of the interviews. **Materials**

Eligibility survey. The lead author sent individuals who expressed interest in participating a link to an online survey hosted in Qualtrics. The purposes of this survey were to determine whether participants met the inclusion criteria and to collect their contact information. The survey collected basic information including age, gender identity, race/ethnicity, disability status and type, educational attainment, level of access to relevant technology, and email address. A total of 41 people completed a survey; three of these individuals did not meet the eligibility criteria for age (n = 1) or for having a visible physical disability (n = 2). Twenty people who took the survey did not complete an interview because they failed to respond to the scheduling request (n = 18), or did not answer the call at the scheduled time nor respond to requests to reschedule (n = 2). Three people took the survey after we reached data saturation but prior to the survey closing.

Interview guide. We developed interview questions and prompts (see Figure 2.1) based upon relevant domains of objectification and body conceptualization theories (Franzoi, 1995; Frederickson & Roberts, 1997; McKinley & Hyde, 1996) and feminist disability theory (e.g., the ways in which their disability-related identities and experiences influence their ideas about body image; Garland-Thomson, 2002). We developed the interview protocol in accordance with sequencing guidelines set forth by Spradley (1979)

and included sample prompts for each question. We designed prompts to enhance participants' descriptions of their experiences and ideas to allow for more thorough exploration and discussion of emerging concepts. We added Question 8 ("What does the term, 'body functionality' mean to you?") to the interview guide after conducting the eighth interview, as it became apparent through analysis and reflexive journaling that body functionality was a complex topic of discussion for study participants.

1. To start, tell me about how you get yourself going in the morning.

- Do you have a routine or is every day different?
- *Tell me about <u>this</u> morning.*

2. As you know, this study is about body image and health. What does the term "body image" mean to you?

- *How did you come to that definition?*
- Is body image about how <u>you</u> think about your body?
- *Is it about how <u>others</u> think about your body?*

3. How would you describe your body image on a typical day?

- What do you focus on?
- Would you say, overall, that you have a positive, negative, or neutral body image?

4. What about your body do you like the most?

5. What about your body do you like the least?

6. Based on above answers:

<u>If mostly appearance-related answers</u> – So, I'm hearing you talk about how your body looks or your appearance. I wonder if you might talk a bit about things your body *does*. <u>If mostly functionality-related answers</u> - I'm hearing you talk about the things your body does. I wonder if you might talk about how your appearance, or how your body looks. 7. What are some of the ways you and other women you know talk about your bodies?

- Who do you talk to?
- *How do these conversations arise?*
- *Is there a difference between how you talk about your body with women with disabilities?*

8. What does the term "body functionality" mean to you?*

9. How, if at all, does your disability influence the way that you think about your body functionality?

10. How, if at all, does your disability influence the way that you think about appearance?

11. How might you describe the relationship between appearance and body functionality?

12. Is there anything else you expected me to ask that I didn't?

13. Is there anything else you'd like to say that you think is important for me to know?

*We added this question to the interview guide after completing the eighth interview, so not all participants answered.

Figure 2.1. Semi-structured interview guide

Procedure

Participant recruitment began after we obtained ethical approval from the UNC Charlotte institutional review board. The lead author created a Facebook post on her personal page, which was shared by regional and national disability researchers and advocacy groups. Another research team member also shared recruitment information on several disability studies ListServs. Recruitment materials directed interested participants to the eligibility survey. The lead author emailed participants deemed eligible to schedule an interview.

The lead author conducted interviews between May and August of 2018, using FaceTime or Skype video calls for interviews when possible. We offered accommodations; for example, two participants completed audio-only interviews due to disability-related challenges placing and using the camera on their mobile phones without assistance. Audio, but not video, was recorded. Interviews began with a review of the consent form that all participants received via email at the time of scheduling. Participants gave verbal consent to participating in the interview and having their words audio-recorded. Participants also chose their pseudonyms at this time. The interviewer then proceeded with the interview. The interviewer began all interviews the same way; yet accommodated the flow of the conversations by adding questions and/or asking questions out of order. Interviews ranged in length from 17:38 to 54:58. Participants received \$20 Amazon.com e-gift cards.

Analysis

The lead author verbatim transcribed recordings within 72 hours of interview completion. The lead author also typed handwritten notes taken during interviews and

reflexive journals written immediately following interviews. After transcribing, the lead author engaged in "pre-coding," (Layder, 1998; Saldaña, 2016) by reading through interview transcripts and highlighting notable quotes and words from each. The lead author then uploaded the transcripts to QSR International's NVivo 12 software for coding and analysis. Consistent with formative literature on grounded theory, we used *in vivo* coding, or coding that retains the participants' original words and phrasing, in the first cycle coding process (Charmaz, 2008; Miles, Huberman, & Saldaña, 2014). We coded the first and second interviews and created the initial codebook based on *in vivo* codes from these two interviews. We used simultaneous coding, including focused and descriptive methods, in the second cycle coding process to categorize and merge similar codes within and across interviews to create categories. Data collection and analysis after the first two interviews followed the constant comparative method (Glaser & Strauss, 1967): we coded transcripts and then compared each with all previous interviews and with the study codebook. We revised the codebook between each interview to reflect changes such as new codes, renamed codes, merging of multiple codes, categorizing of codes, and deletion of codes that faded out (Charmaz, 2008) until we reached saturation and no such changes were necessary. We extracted and analyzed themes and subthemes based on their emergence across cases and their explanatory value within cases. We used diagramming (Buckley & Waring, 2013) to illuminate intersections of codes and themes to develop the preliminary conceptual model.

Qualitative Rigor

We used several techniques to enhance the study's rigor (Lincoln & Guba, 1985). To enhance the study's credibility, the lead author conducted member checks. Within ten days following each interview, the lead author emailed a summary of the interview to each participant and asked her to confirm or correct it to ensure it accurately reflected what she shared during the interview. One participant requested we add a sentence to the summary to reflect her partner's positive influence on her body image. Another participant pointed out one typing error. Participants checked and confirmed all other summaries without revision. The use of multiple coders also enhanced credibility; the second author used a clean copy of the codebook and relevant transcript for coding two interviews early in the data collection process. The lead author and faculty supervisor also met approximately every other week for peer debriefing meetings (Lincoln & Guba, 1985) during which the coding, analysis, and theorizing done by the lead author was discussed with, and often challenged by, the faculty supervisor. We resolved discrepancies between coders and updated the codebook to reflect these analytic decisions. To enhance the study's dependability, the lead author kept an audit trail of all study decisions by keeping detailed field notes and practicing reflexivity (Ortlipp, 2008; Tracy, 2010). Other types of triangulation, such as the use of multiple theoretical lenses to conceptualize the study, further strengthened its rigor.

Results

Four major themes emerged from the interviews: a) *meanings and definitions*, which includes participants' definitions of body image and body functionality; b) *body image stability*, which includes participants' insights about fluctuations in body image; c) *factors that influence body image*, which presents how participants described several factors that influence their positive and negative body image; and d) *interaction of appearance and functionality*, a novel concept emerging from the interviews that includes participants' accounts of the ways body functionality and appearance interact to influence their overall body image. We present major themes and their various subthemes below, supported by direct quotations from participants. A conceptual model derived from study findings is found in Figure 2.2.

Meanings and Definitions

Body image. We asked participants early in the interviews to describe what the term "body image" meant to them. Overall, participants defined body image in a holistic way, including internal and external views of the body, recognizing its positive and negative valences, encompassing appearance and body functionality aspects, and within their definitions. Few participants endorsed stereotypical views about body image, such as that it is a women's issue or that it focuses solely on weight and body size. Participants did not define body image differently based on their disability types and diagnoses.

Body image is comprised of internal and external perspectives. All 15

participants included some statement in their definition of body image pertaining to how a person sees or feels about their own body, or some variation of an *internal* perspective of one's own body. Ten participants also defined body image as how someone else or broader society sees their body. For example, Chloe defined body image as:

...the person's view of themselves and obviously their body and how they feel about themselves, but usually it's also tied to how society views them, or how someone in their family views them. Like, we can't usually talk about body image without mentioning its relation to somebody or something greater than ourselves, you know what I mean? Josette similarly emphasized the importance of this *external* view of the body on overall body image:

It's what you think of your body and how your body reflects onto society, so whether it's a desirable body or not a desirable body. Your body image is a personal thing but it's always the anticipated expectation of what somebody else thinks of your body. So, I think a lot of people's body images are informed by what they might expect other people think about their own bodies.

Body image is positive and negative. Seven participants described how body image could be positive and negative. Grace's definition of body image included these positive and negative aspects: "Body image relates to how good you feel, or bad, in your own skin. Because you can look at it- God knows I've done both- but you can look at it positively or negatively." Marie defined body image exclusively in a positive manner: "I think it has a lot to do with like self-love, like, you know, just finding that inner beauty within yourself."

Body image includes appearance and body functionality. At this point in the interview process, the interviewer had not yet mentioned body functionality. Yet, a third of study participants mentioned aspects of body functionality in their overall definition of body image, suggesting the relevance of this construct to participants' overall body image. For example, Bobbi provided a holistic definition of body image that included aspects of body functionality: "Body image is how I feel about my body at any given time. That means every aspect of the body- not just how it looks, but what it can do and how it's feeling and what it needs." June, who acquired her disability in early adulthood, first defined body image as, "how you feel about your physical self, which could mean

the things that it is able to do, or the way you look, or a mix of both." She went on to describe how her experience of disability changed her definition of body image to include functionality aspects:

Before I had the accident and got very injured, I probably would have, like most young women in their early twenties and late teens, probably focused more on the physical appearance side of body image. I don't think it was until after I had to reflect more on what my physical capabilities were or were not that I would add that other piece to it.

Stereotypical assumptions about body image. Only three participants included in their definitions "stereotypical" views about body image, such as its link to eating disorders, that it is solely negatively oriented, and that it is a women's issue. Part of Bobbi's definition indicated that body image is about, "sort of the usual, eating disorders and um, uh, how people feel about the way they look essentially..." Sophie described body image as "usually" a women's issue. Silver discussed how American women negatively compare themselves to other women:

Body image is defined as how we perceive ourselves in our physical body... and because we live in America, we compare ourselves, and women put themselves down more so in comparing themselves to other women than putting themselves better than other women.

Body functionality. Definitions of body functionality provided by participants typically encompassed holistic views about the body and its functions. Two participants used phrasing such as, "thinking about the body like a machine" (Emily) and "the mechanics of the body and how it all works together" (Silver) in their definitions. Two participants provided more context about their holistic view of body functionality; Catherine defined body functionality as, "…having your body be able to do what it needs to get through your day." Importantly, participants noted that the definition of body functionality should include what the body can *and cannot* do, and what it *does differently*. Kristen, for example, defined body functionality as, "…how my body works, how it should work, and how it doesn't work." Marie described how differences in function should be taken into consideration in defining body functionality:

I think one of the things that you have to remember about people who aren't functioning as "normal" is that they're still functioning... I think I say something along the lines of, "I can do pretty much anything, but I do it differently."

Body Image Stability

We asked participants to describe their body image on a typical day. Charlotte and Kasey both initially responded to this question by saying, "It depends on the day!" and Catherine and Josette both responded by saying they experience "fluctuations." Nine participants in total explicitly described experiencing fluctuations or instability regarding their body image. When prompted further to describe factors influencing the fluctuations, participants described how their body image often aligned with their health symptoms (including those related and unrelated to their disabilities), which for some, fluctuated daily.

Health symptoms. Nine participants described experiencing mental and physical health symptoms that influence their day-to-day experiences of body image.

Mental health symptoms. Mental health symptoms emerged as a significant factor influencing body image stability; four participants endorsed this sub-theme. Emily

indicated, "I think it has to do with the mental health issues, honestly. Like... how good I feel about what I'm doing and how motivated I am to get things done during the day." Charlotte said her body image "fluctuates around how [she's] feeling mentally that day." Josette further identified stress as a mental health component influencing her body image: "I definitely experience fluctuations; sometimes I feel great, and sometimes I don't. Generally if I'm more stressed out, I'm already more likely to start to get down on myself."

Physical health symptoms. Five participants discussed how their physical health symptoms affected their fluctuations in body image. Pain associated with disability emerged as a physical symptom that affected body image stability for two participants. June described how having chronic pain made it difficult to feel positively:

I do have chronic pain, so during times when my chronic pain is worse, it's difficult to feel super perky about your body when that's happening. Those are the times when you, you know, like kind of feel... you feel kind of stuck.

Kristen had a more nuanced experience, describing her awareness of how her pain level manifests on her face, thereby changing her appearance: "When I'm in excruciating pain, I know early on in my injury, I didn't realize that it affected the way I appear to others. So I'm very intentional about, um, making sure that my face doesn't reflect my function."

Emily discussed other physical health symptoms, such as changes in her menstrual cycle resulting from her injury. She described symptoms related to her menstrual cycle, such as bloating, as significant and unpredictable factors influencing her body image: "And [the bloating] fluctuates so much and I hate that it affects my mood and how I feel about myself, but it does." Finally, Sophie described how a recent diagnosis of a new health condition negatively affected her body image:

I have been dealing with this lung issue, you know this rare lung condition that was just diagnosed about a month ago, even though the symptoms have been occurring for close to two years. So that's been something that I've had to deal with. And since that's come up, it's sort of, taken a chunk out of how I view myself.

Factors that Influence Body Image

All 15 participants described numerous factors related to body functionality and appearance that influence their body image, including aspects of negative and positive body image. Participants also discussed factors related to an interaction of or relationship between body functionality and appearance; however, we present those factors under the fourth theme.

Body functionality factors. Participants more often linked body functionality factors to negative body image.

Bladder and bowel functionality. Four participants discussed how differences in their bladder and bowel functionality negatively influenced their body image. Charlotte described how wearing adult underwear makes her feel negatively about her body:

I wear like, adult underwear. But, like, when I'm alone, I'm not capable to go to the bathroom by myself... on the good days I can take it okay, but like, if I'm not having a good day, I feel almost worthless and disgusting, you know? Kasey similarly described how a lack of control of her bowel and bladder function negatively influences her body image: "I like, can't control my bowel and bladder. So that's always something that I can be concerned about... I think that's probably one of the main things that definitely affects how I feel about my body."

Functionality comparisons. Another factor influencing body image described by six study participants was engaging in upward and downward body functionality comparisons with others. For example, participants specifically discussed being grateful for and appreciating their bodies' capabilities when reflecting on the fact that others had more significant disability-related challenges. Grace stated, "I know some people that don't- you know, can't move their body from the neck down. So I consider myself pretty lucky." Chloe further explained that she appreciates that her body does not stand out as much as other people with disabilities' bodies might:

I don't mean it against anybody else with a disability, but to me my body is not as disabled or deformed as other people's bodies. So um, of course you can tell I'm disabled because when I'm out in public because I have my wheelchair glued to me, but I don't stand out in other ways, I don't think. Not as much as other people might. I'm picking on stereotypical things, like I don't have a bent spine, or drooling, or things that other people that are able-bodied might see as not beautiful.

On the other hand, study participants made upward comparisons to able-bodied women and described a functional ideal to which they compare themselves; these discussions tended to related to negative body image. Kasey, for example, discussed difficulties finding a partner: "It's like I can't really compete with an able-bodied woman. I shouldn't have to anyway, but you know what I mean. Sometimes there's just no point in even trying, or putting myself out there as much." Bobbi discussed comparing herself to a functional ideal, resulting from what she described as "internalized ableism."

We have this concept of what the functional body is, and if it doesn't meet that goal or expectation, um... you're going to have internalized ableism. Particularly for people who have an acquired disability, who can remember what life was like functionally beforehand. You know, there's that idea of "I should be this other way."

Appearance-related factors. Participants were more likely to discuss aspects of their appearance in the context of positive body image.

Facial features and hair. When asked what they liked most about their bodies, nine participants mentioned facial features including their eyes and smiles and their hair. Bobbi provided context for this phenomenon: "It's probably my face because it has the least amount of symptoms. And that's something I'm able to take care of more, so it's just easier." Marie was one exception; when asked what she liked about her body, she described that she liked her disability because it gave her an opportunity to stand out:

I like that I'm different. I like that there's something different about me. I don't know why. I mean, well, I do know why. I like to stand out, and so I really, actually enjoy that my legs are not the same, so that's why I wear shorts and capris and skirts and dresses, because I like to show that off.

Interaction of Appearance and Body Functionality

The final major theme emerging from these data was an interaction of the constructs of appearance and body functionality; participants expressed significant

concerns about their appearance while engaging in a range of body functions. This theme was the most frequently endorsed theme in the study and was discussed by all participants. Silver described this phenomenon by saying, "If you just look at me standing up, I look great... I'm lookin' pretty good! If you look at me in a photograph, I'm pretty good! But when I start walkin', it all changes. Everybody's image of me changes." Other participants used phrases such as "appearing capable" (Josette), "looking disabled" (Kristen), and "looking like there's something wrong with me" (Bobbi) when discussing the complex and multi-faceted interaction of appearance and body functionality.

Eating. Two participants described how their appearance while eating was a significant concern, despite describing themselves as having an overall positive body image. Tammy, for example, described her overall body image as "neutral to positive," yet expressed, "I am very conscious about what I look like doing things. So I'm very self-conscious about especially eating." Sophie also mentioned she "avoided eating at the dining hall" at her school because of her self-consciousness about her "oral-motor issues."

Clothing and dressing. Participants described often thinking about how or taking steps to more closely match culturally dominant body norms; in other words, they described using or focusing on their appearance to detract from or "compensate" for limitations in body functionality. Ten participants mentioned using *clothing and dressing* to assimilate in this way. June described making sure she was "dressed nicely, because I knew that if I was going to be walking through my school with two crutches or a cane, everyone's staring at you and you might as well not give them one more thing to look at you too long for." Chloe described dressing in "colorful outfits and, you know, big earrings and things" to stand out in a way that was not related to her disability.

Participants sometimes described clothing and dressing as appearance-related factors influencing body image. Interestingly, though, participants also discussed how their body functionality often made it difficult for them to dress (i.e., appear) in a way that allowed them to "fit in" to society, exemplifying the interaction of functionality and appearance. As Bobbi described:

Something I focus on every day... because of my [disability], I have difficulty wearing regular clothing, for example. So I would say that that comes down to a huge part of my body image, is, how can I dress myself to um, sort of fit into society? In a way that is not going to cause me more issues?

Kristen also discussed how her functional challenges affect her dressing, which influences her overall body image:

Because of how difficult it is for me to get dressed and undressed, I have to plan my entire day on one wardrobe, like I can't wear something in the morning and something else in the afternoon... so there's a lot of times I'm over-dressed and under-dressed, trying to find the common denominator there.

Kristen also described how clothing and dressing could be somewhat of a doubleedged sword; she used her clothing to make herself feel good and signify physical and intellectual capability, but also described how not looking "disabled enough" was a problem when attempting to acquire needed disability services and supports:

So I am sometimes seen as not disabled enough... The people that see me that way are the ones that get to decide whether or not I receive disability services. If I happen to have makeup on and I'm dressed in a way that makes me feel better about myself, I should not be told that there are other people who need services more than I do because they look more disabled... It almost feels like my appearance is more important than my diagnosis.

Grace described how having access to adaptive clothing, lingerie, and jewelry in which she was able to dress herself significantly and *positively* influenced her body image. For example:

I remember the first time- talk about a positive body image experience- a friend of mine bought me a necklace, and I went to ask her to put it on because I can't clasp it. And she said, "Oh no, it has a magnet!" ... that was so cool, and I wore it at least once a week, because it was something I could put on myself. It's those kinds of things, in those kinds of moments where I get the best body image, because I can do it myself.

Weight, body size, and body composition. Participants discussed weight, body size, and body composition as an appearance-related factor intrinsically linked to their body functionality that influenced their body image, usually negatively. Participants often related changes in their weight, body size, or body composition to their disabilities. For example, several participants described how their disabilities affect the level and type of physical activities they are able to engage in, often resulting in weight changes over time and/or changes in their musculature. For example, Kristen described weight gain resulting from her wheelchair use, in addition to changes in her body composition (e.g., musculature) that she does not like: Since I've been in a wheelchair, I've gained weight, you know, because I'm not as physical... So this is the biggest I've ever been physically. And um, while I use both manual and power chairs, my shoulders reflect the movement that's required for me to use a manual chair. And so that's gotten really big and I don't like that. Emily also discussed changes in her body composition following her injury:

I lost about 30 pounds after my injury, um, which, most of it was muscle. Um, so my body's changed a lot and a lot of my skin is sagging on those muscles that haven't quite come back yet. Um, so that, that's hard to see every day.

Finally, Susan described how she and other women with disabilities discuss their abdominal area concerns: "We all refer to our belly as the 'para-belly' because a lot of us can't work those abdominal muscles. So we constantly look like we're four months pregnant."

Mobility aids and adaptive devices. When asked about the relationship between appearance and body functionality, participants often mentioned their use of *mobility aids* (e.g., wheelchairs, walkers, crutches, canes, and prostheses). Participants expressed thinking of these aids as integral to their bodies' functionality; however, participants were also aware of how these aids tend to be seen and perceived by an ableist society. Tammy discussed how experiencing *ableism* affected her body image:

We have an extra layer of added worry, I guess. And I think especially that can come from if you use some sort of mobility device, whether it's a wheelchair or a walker, because if you rely on that thing, that kind of is like your body. And I think most of us are aware that when people look at us, the wheelchair... it's kinda like the first thing they see. I think that can influence your body image a lot. Susan also described people's perceptions of her wheelchair, stating, "they don't look at me, they look at my wheelchair." Catherine took this discussion a step further, describing that people "just see the chair" and "assume things about [her]- that [she's] not a capable person because [she's] in a wheelchair." She went on to discuss engaging in physical functions – some that she considered dangerous for herself – to show her capabilities:

At work, I will do things- I'll do the extra evaluation, or I'll meet with the next client even before I've eaten lunch and it'll be like 2:00. Because I don't want people to think I can't do it. I'll kick chairs out of my way or lift things that I shouldn't be lifting. I've lifted chairs out of my way just to prove to people that I could do it. [I've] opened really heavy doors with my feet that I shouldn't be doing, because I could probably break a foot because I can't feel it- but yeah, kicking them open or kicking things out of my way, or things like that, to show people that I'm not um, I'm not incapable. I'm not incapacitated.

Josette also described engaging in physical functions to "appear capable" to others: Recently my wife and I bought a van, and we were trying to decide if we should get a ramp van, because we both use wheelchairs and it's convenient, or if we should get a van where we could sort of put our own wheelchairs in ourselves. And for many reasons, but this was one of the more surface reasons, was that I just didn't want to look that disabled yet. I wasn't ready for that. So like, the act of putting my own wheelchair into the car is sort of like a public display of how capable I am. **Aging.** Participants expressed concerns about how the interaction between their appearance and body functionality may change as they are aging. Kasey noticed that as she aged, she experienced atrophy due to her injury, which affected her appearance:

Since turning 40, it's gone a little downhill... When I got injured, you know, I hadn't really atrophied yet and all that stuff, and still was feeling. It seems like since I hit 40 the weight has started to come on, and I can't get rid of it as easy, so that's really irritating.

Chloe also expressed concerns about her body image as she ages due to changes in her function that may influence her appearance: "I just think about how that might affect my body image like, oh, I don't feel like dressing up today because I'm in such pain. I don't want to move this way right now."

Conceptual Model

We developed a preliminary conceptual model (see Figure 2.2) based on study findings. We represent each of the emergent themes and subthemes within the model. Study participants believed *body image* encompassed *body functionality, appearance,* and an overlap of those two domains, which we have named *functional-aesthetic body image*. Participants also indicated that body image was comprised of *internal* and *external* views and *positive* and *negative* valences. Subthemes that emerged under appearance (e.g., *facial features and hair*) and body functionality (e.g., *bladder and bowel function* and *functionality comparisons*) separately are placed within those domains, peripheral to the overlapping domain. Subthemes that were described by participants as representing the interaction or relationship between body functionality and appearance (e.g., eating; weight, body size, and body composition; mobility aids; and

aging) are centered within the functional-aesthetic body image domain.



Figure 2.2. Conceptual model developed from study findings, adapted from Franzoi's (1995) body conceptualization theory

We placed the *health symptoms* subtheme on the line between body functionality and functional-aesthetic body image; participants usually described their health symptoms as a concept of body functionality, but some participants discussed how experiencing pain affects their appearance. Likewise, the *clothing and dressing* subtheme is placed on the line between appearance and functional-aesthetic body image; clothing and dressing were usually discussed as a way to enhance one's appearance, however some participants talked about how their functional limitations in dressing affected their appearance. More research is needed to clarify the placement of these two subthemes.

Discussion

The present qualitative study used a grounded theory approach to explore meanings of and experiences with body image, with a strong emphasis on body functionality, among women with visible physical disabilities. Study findings both confirm previous research and present novel perspectives that substantially expand the breadth of current knowledge about the construct of body functionality as it relates to overall body image.

Women in the present study provided definitions of body image that reflect a holistic view, encompassing positive and negative valences, internal and external perspectives, and focusing not only the appearance of the body, but its functionality. Interestingly, findings regarding the ways women with physical disabilities define body image both align with and diverge from definitions presented by similar populations in previous research. For example, a recent study exploring definitions of body image among members and student trainees of an exercise facility for people with disabilities and chronic conditions similarly found that some participants held holistic definitions of body image aligned with those of the research community (e.g., including body function and positive body image; Bailey, Gammage, & van Ingen, 2017; Tylka & Wood-Barcalow, 2015). However, their sample more frequently endorsed stereotypical assumptions about body image than the current sample, particularly when emphasizing weight or body size in their definitions of body image (Bailey et al., 2017). One possible

explanation for the discrepancies in these findings could be that Bailey et al. (2017) recruited a more heterogeneous sample including people with and without disabilities, older adults, and students, and also that they recruited their sample from (and conducted interviews and focus groups within) an exercise facility, where members and employees may have been more likely or contextually primed to focus on weight.

This is the first known study to elicit definitions of body functionality from those outside of the research community. Participants' definitions confirmed some aspects of the definition currently accepted in the literature in that they believed body functionality encompasses a range of bodily processes and is not solely focused on physical abilities. Participants also offered additional perspectives that support reevaluating the definition and theoretical placement of the construct. For example, participants in the current study indicated that the definition of body functionality must recognize what some bodies *cannot* do, and that many bodies function *differently*. Study findings also indicate that women who have visible differences in their bodies' functionality frequently link body functionality to negative body image. Emphasizing solely what the body *can* do, and considering it only a *positive* body image experience might be interpreted as ableist, in that it is complicit in the erasure of the lived experiences of women with visible physical disabilities and some of the most salient aspects of their embodiment (Garland-Thomson, 2002; Shakespeare & Watson, 2002).

Women with visible physical disabilities in the present study endorsed the idea that both positive and negative body image can be context-dependent states that fluctuate temporally and with health and disability symptomatology, rather than stable traits. This finding supports previous qualitative research exploring positive and negative body image among people with disabilities and health conditions (Bailey et al., 2015; Pearce, Thogersen-Ntoumani, Duda, & McKenna, 2014; Posen et al., 2000; Sheldon, Renwick, & Yoshida, 2011) and quantitative research with other non-clinical populations (e.g., Albertson, Neff, & Dill-Shackleford, 2014), providing additional evidence that positive and negative body image are not solely stable traits (Tylka & Wood-Barcalow, 2015). Despite this scholarship, researchers still largely consider body image a cross-situational, constant trait (Cash, 1990; Cash, Fleming, Alindogan, Steadman, & Whitehead, 2002; Tiggemann, 2001), which may present significant concerns in the accurate measurement of body image fluctuations described by the current sample, researchers working with people with disabilities or other clinical populations whose health symptoms may influence their body image should attempt to use state *and* trait measures of body image variables, and should also consider collecting information about study participants' symptoms and overall self-rated health when administering body image measures.

Women with visible physical disabilities in the current study discussed numerous factors that influenced their positive and negative body image, regarding body functionality and appearance. Perhaps the most significant finding of the present study was that women in the present study conceptualized appearance and body functionality as sometimes distinct, but often intersecting constructs that influenced their overall body image. Study findings may help explain the mixed results of previous studies assessing whether focusing on body functionality can promote positive body image and reduce negative body image outcomes among women. Previous studies of body functionality have involved experimental manipulations eliciting both internal body functionality perspectives (e.g., writing about *one's own body* in functionality terms; Alleva et al., 2014) and external body functionality perspectives (e.g., viewing others' bodies "in process" or on functionality-related poses; Mulgrew & Hennes, 2015; Mulgrew & Tiggemann, 2018). Current study findings further suggest that the discrepancy between these results may relate to the fact that many body functions are *visible*, and therefore may be evaluated, judged, and, in the case of participants in the present study, stigmatized by others. Future intervention research should consider testing whether focusing solely on internal body processes that cannot be or are not usually visible to others elicits more positive body image outcomes. Additional research should also investigate how different groups conceptualize the visibility of body processes; for example, people possessing "typical" body functionality might consider bladder and bowel function to be internal or not visible, whereas people who have stomas or use catheters may differently evaluate this bodily experience.

Limitations

In the present study, no members of the research team represented the specific population studied. We used several techniques to balance this shortcoming; first, individuals with disabilities and disability advocates reviewed the study materials (e.g., the consent form, recruitment announcements, and interview guide) prior to study implementation to ensure the terminology and phrasing were acceptable and relevant to the community. We completed recruitment primarily through two authors' personal connections in the disability community to gain participants' trust. The member checking process also served as a way for participants to appraise the lead author's interpretations of their words and experiences to ensure interpretations by researchers who either do not have disabilities, or whose disabilities differed in type from participants', did not misrepresent the community.

Some participants completed only phone interviews, rather than video interviews, due to challenges placing and operating a phone or camera without assistance. Thus, some participants were face-to-face with the interviewer and others did not have that same level of interaction. Although this discrepancy in study setting can be considered a methodological limitation, it is also a strength in terms of providing a model for including individuals with disabilities within research. Only allowing participants who could position their own cameras or those who have access to personal care on a regular basis may discourage people with more advanced functional challenges or those with lower socioeconomic status from participating.

The use of web-based recruitment methods, a web-based eligibility survey, and interviews over video-conferencing or phone undoubtedly allowed only those with access to Internet-enabled devices and an email address they check regularly to participate, precluding individuals with some of the most significant health and disability-related challenges from accessing the study. This limitation is likely to have resulted in a highly educated sample; women in the present study may face fewer challenges than those with lower socioeconomic status. Future studies should consider also using word-of-mouth recruitment strategies, paper-and-pen surveys, and in-person interviews to access individuals representing a broader range of demographic backgrounds. Lastly, we only asked a proportion of study participants to define body functionality. We encourage researchers to conduct additional qualitative studies to better understand the meanings and experiences of body functionality among individuals with disabilities and within broader populations.

Strengths

Limitations of the study were balanced by several conceptual and methodological strengths. Notably, the present study drew from the concepts of Universal Design for Research (Williams & Moore, 2011) to facilitate the inclusion of women with disabilities. The study used web-based technologies to minimize or eliminate physical and environmental barriers to participation. Reasonable accommodations also facilitated the participation of women with widely varying levels of functional ability, which likely enhanced the breadth and depth of data provided by the sample.

This study also used several techniques to enrich qualitative rigor. The extensive use of participant quotations to demonstrate emerging themes and subthemes and the member checking process enhance the credibility of the study findings (Lincoln & Guba, 1985). Rich descriptions of the research methods and personnel enhance the study's dependability (Lincoln & Guba, 1985). Triangulation of data using multiple coders and several theoretical models and the lead author's reflexive process throughout data collection and analysis further strengthened the study's trustworthiness (Lincoln & Guba, 1985).

Future Directions

Many important functions our bodies engage in are visible to ourselves and to others. Women in the present study intrinsically linked this visibility of their bodies' body functionality to their appearance concerns. It will be important for future research to explore this phenomenon among other populations, including non-disabled women. Additional qualitative studies designed to fully explore all the domains of these concepts are recommended. We also encourage researchers to collect and analyze demographic data about disability status and type, much the same as they would data about gender identity, race/ethnicity, age, and socioeconomic status in all body image studies. Disability is a highly prevalent and critical aspect of identity that may significantly influence individuals' body image outcomes and experiences. Collecting and reporting data about this demographic characteristic will only strengthen the field's science and demonstrate its commitment to diverse populations.

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CHAPTER 3: UNIVERSAL DESIGN FOR MEASUREMENT: CENTERING THE EXPERIENCES OF INDIVIDUALS WITH DISABILITIES WITHIN SCALE DEVELOPMENT RESEARCH

Abstract: People with disabilities comprise over 25% of the US adult population, yet remain underrepresented in mainstream health research. The lack of measures of common constructs that have been validated in, but are not specific to, this population may be a barrier to their inclusion. This paper describes the use of Universal Design for Measurement (UDM), a novel method for developing self-report scales that are validated among the broadest possible populations while minimizing the need for scale adaptation, in the development and initial content validation of a new body image scale. We derived 30 initial scale items primarily from a qualitative study of body image among women with physical disabilities, and assessed content validity by surveying subject matter experts (SMEs; N = 6). We conducted a two-round online Delphi panel study to gain consensus about items among community women with (n = 18) and without (n = 15)disabilities. Overall results show that most scale items were judged to be acceptable by SMEs and community women, and that the Delphi panel approach was successful in gaining consensus about most scale items from women with and without disabilities. Findings provide valuable metrics to guide further scale revision and suggest that UDM may be a promising approach to facilitate the full inclusion of people with disabilities within mainstream health research.

Introduction

Approximately one in four US adults have some type of disability (Okoro, Hollis, Cyrus, & Griffin-Blake, 2018). People with disabilities face some of the most substantial health disparities regarding their health outcomes and behaviors and their access to health care. They are four times more likely to report poor to fair health than adults without disabilities (40.3% vs. 9.9%; Altman & Bernstein, 2008) and have a nearly three-fold higher incidence of diabetes (19.1% vs. 6.8%) and prevalence of cardiovascular disease (12.4% vs. 3.4% [ages 18-44] and 27.7% vs. 9.7% [ages 45-64]; Krahn, Klein Walker, & Correa-de-Araujo, 2015). People with disabilities are more likely to engage in no leisure-time physical activity and to smoke than those without disabilities (28.8% vs. 18.0%) and are more than twice as likely as those with no disabilities to go without needed health care due to financial barriers (Krahn, et al., 2015).

Factors influencing these and other health inequities among people with disabilities are well documented. Individuals with disabilities receive inadequate screening and preventive services due to shortages of adequately trained providers and a dearth of accessible facilities (World Health Organization, 2018). Discrimination toward individuals with disabilities within the health care system is another influential factor (Moscoso-Porras & Alvarado, 2018). Deficient epidemiologic surveillance of health issues among people with disabilities also indirectly affects these health disparities. Without conducting population-based research that is inclusive of those with disabilities, researchers and clinicians cannot reliably compare health issues among people with and without disabilities, therefore precluding their ability to adequately address disability health disparities (Williams & Moore, 2011). Although *Healthy People 2020* specifically aims to increase the number of national data systems incorporating six standardized disability identification questions (US Department of Health and Human Services [HHS], 2014; HHS, 2011), this increased population-level surveillance has not instigated broader awareness of disability inclusion nor uptake of disability demographic questions by independent investigators conducting health research (Rios, Magasi, Novak, & Harniss, 2016). People with disabilities are severely underrepresented in mainstream health studies (National Council on Disability, 2009).

Universal Design for Research has been proposed to address the exclusion of people with disabilities from mainstream health research (Williams & Moore, 2001). This framework was built on the principles of Universal Design (Mace, Hardie, & Place, 1991; Story, Mueller, & Mace, 1998), initially developed for use in the field of architecture. The goal of Universal Design is to create physical spaces and tools that are accessible to the broadest possible populations while minimizing the need for accommodations and modifications (Mace et al., 1991; Williams & Moore, 2011). Universal Design for Research, then, supports the design of research studies that are accessible to the broadest possible groups while minimizing the need for modifications or to conduct separate studies (Williams & Moore, 2011). Universal Design for Research guidelines include: (a) recruiting potential participants who meet the study inclusion criteria regardless of their disability status; (b) refraining from creating disability-related exclusion criteria unless there is scientific or medical rational to do so; (c) providing multiple, flexible pathways by which participants can be recruited, engage in the informed consent process, and complete study procedures; and (d) inviting individuals with disabilities and/or people

who have expertise working in the area of disability research to help design research studies (Williams & Moore, 2011).

Universal Design for Research is a promising approach to promote the inclusion of people with disabilities in mainstream research; however, the framework is underdeveloped in addressing the need for measurement instruments that have been developed and tested with the experiences of those with disabilities in mind. The lack of measures of common constructs that have been validated among people with disabilities, but are not solely designed for use in this population, may be a significant barrier to their inclusion in mainstream health research. The National Council on Disability (2009) included a specific call for universally designed health research and measurement as a step toward improving health equity for people with disabilities. Universal Design principles have the potential to further apply to the field of measurement–particularly to the development and testing of self-report scales.

The Present Study

This research supports another application of Universal Design to the development and testing of measurement instruments, termed Universal Design for Measurement (UDM). The UDM approach has the potential to advance the field of health disparities research by guiding the equivalent measurement of relevant social and healthrelated constructs across demographic groups, thereby enhancing researchers' abilities to estimate the true effects of health inequities within broad populations. This manuscript presents the results of two studies describing the development and content validation of a new body image scale designed for use among all women regardless of their disability status. We derived Initial scale items primarily from qualitative interviews with women with disabilities and supported by additional empirical research. In Study One, we tested the initial item pool and the scale instructions and response options with a panel of subject matter experts. In Study Two, we invited community women with and without disabilities to rate and comment on the items to generate consensus on the content. We discuss implications of each study, and propose guidelines for the UDM framework.

Formative Research and Item Generation

The construct of interest in the present study is functional-aesthetic body image (FABI), defined as the thoughts and feelings a person has about, and their behaviors related to, how they look to themselves and to others while engaging in body functions (Vinoski Thomas et al., 2019). This construct emerged from qualitative interviews on the topics of body image and body functionality with women with visible physical disabilities between the ages of 18 and 55; however, the concepts women discussed that led to the emergence of FABI were sometimes unrelated to their disabilities and may also be applicable to women who do not identify as having disabilities. This research provided the rationale for conducting the present scale development study in line with the principles of Universal Design for Research.

We generated a pool of 30 items intended to measure FABI from the qualitative data. Participant quotes that we coded with the FABI theme were extracted and adapted into scale items (see Table 3.1). We retained participants' terminology and phrasing where possible. Items 3 and 21 were adapted from the Embodied Sense of Self Scale (Asai et al., 2016) and the Amputee Body Image Scale (Breakey, 1997), respectively. Item 11 received empirical support from research describing the relationship between pain and appearance (Suendermann, Rydberg, Linder, & Linton, 2018).

Items	Supporting Quotes	Domain
1. I worry about how I look while I am exercising or doing physical activities.	n/a	Affective (satisfaction)
2. I am more concerned about how I look in videos of me moving (e.g., talking, laughing, walking) than how I look in still photos.	"If you just look at me standing up, I look great I'm lookin' pretty good! If you look at me in a photograph, I'm pretty good! But when I start walkin', it all changes. Everybody's image of me changes."	Affective (satisfaction)
3. I dislike seeing my reflection when I'm doing an activity (e.g., walking by a glass storefront, engaged in an activity in front of a mirror).	"So like, when I see myself walk in the mirror, full-length mirror I mean, I look at myself and I go, oh, I don't want to look at myself walk because if I look at myself walk in the mirror, it makes me more self-conscious and then I get tighter and then it gets more ugly to me when I walk."	Affective (satisfaction)
	*Adapted from Embodied Sense of Self scale (Asai et al., 2016)	
4. I worry that my body movements look awkward.	"I feel like look awkward sometimes. With my disability, my movements are just kind of awkward, and so that functioning kind of reflects on my appearance because I'm self-conscious about what um, how, what I'm doing appears like that."	Affective (satisfaction)
5. The way my body looks while I'm engaged in specific activities is important to my overall sense of self.	n/a	Cognitive (values)
6. I compare the way <i>my</i> body looks while doing specific activities to how <i>others</i> ' bodies look while doing those same things.	"I think those days are, they look like a lot of comparing. Comparing me to someone else or comparing myself to someone else and not feeling like I'm good enough on a certain level"	Behavioral (investment)
7. I make an effort with my appearance so that people will want to talk to or build relationships with me.	"I like to be a girl and wear makeup and make my hair pretty and wear heels even though I can't walk. I like to appear in such a way that people are willing to ask the question, what's wrong with you? Why are you in a wheelchair?"	Behavioral (investment)

Table 3.1. Qualitative and empirical support for FABI items

8. I am concerned that as I get older, changes in my body's functioning will affect how I look.	"I'm just afraid I won't have as good a body image when I get older. I mean, I hope I do, but I feel like I'm human too, so I might not like all those wrinkles, or skin tags, or pain, or bruises, or like you know, I feel like I'm gonna come to that point where sometimes I'm like, 'Aww that doesn't look good on me.""	Affective (satisfaction)
9. I am self-conscious about how I look when I eat.	"I hate when people are like watching me do something or like just like watching me eat. I feel very nervous because when I'm thinking about is gosh, I probably look weird trying to do this or something like that."	Affective (satisfaction)
	"Between the gastro and the oral-motor issues, it can be difficult to eat out like in public sometimes, or that can be something that I feel pretty self- conscious about"	
10. I am concerned about how I look when I am talking and laughing with others.	"I have a double chin when I do this [tilts head down and makes a frowning face], I do that all the time, 17,000 times throughout the day and I don't even know that I'm doing it until I take a picture of myself. And so I think um, and so like everybody else can actually see that."	Affective (satisfaction)
11. I worry that my appearance is worse when I feel physical symptoms (e.g., pain, exhaustion, illness).	*Adapted from Suendermann, Rydberg, Linder, and Linton's (2018) research about the effects of chronic pain on appearance	Affective (satisfaction)
12. It is important to me that I appear as physically capable as possible.	"Like I feel really uncomfortable if I'm struggling with a steep hill, or stuck in a parking lot with gravel and I'm getting my casters stuck, um, just any sort of time where I'm looking not so capable is something I try to avoid."	Cognitive (values)
13. I like how I look in certain clothing items when I try them on, but dislike how I look when I'm wearing them and doing activities.	n/a	Affective (satisfaction)
14. I worry about the way others see how my body works.	"It isn't just how I see my body, but how society sees my body. And therefore how society sees how my body works."	Affective (satisfaction)
15. Looking strong and functional is important	"I mean I think of my body as being very functional and um, not in line with the stereotypes	Cognitive (values)

to my overall sense of self.	of disabilities. Perhaps that's one reason why it's very valuable to me to appear strong? Um, and to appear capable."	
16. I make efforts to look as smart or intellectually capable as possible.	"I do think that sometimes I don't appear to be as smart, I guess because I know I have brain injury. So depending on the audience, if I know I'm just going to be maybe in an academic environment, I may not appear as competent."	Behavioral (investment)
17. I wear clothing items and/or shoes that are uncomfortable or restrict my movements because doing so helps me fit in.	"Because of my [disability] I have difficulty wearing regular clothing, for example. So I would say that that comes down to a huge part of my body image, is, how can I dress myself to um, sort of fit into society? In a way that is not going to cause me more issues?"	Behavioral (investment)
18. I engage in specific activities to show others that I am physically capable.	"I'll kick chairs out of my way or lift things that I shouldn't be lifting. I've lifted chairs out of my way just to prove to people that I could do it."	Behavioral (investment)
19. I am concerned about how my body looks during sex.	n/a	Affective (satisfaction)
20. The things I do to enhance my appearance (e.g., how I style my hair, the way I dress) affect the functions and activities I can do.	n/a	Behavioral (investment)
21. Because of my body's functioning, I feel more anxious about my appearance in social situations than when I am alone.	*Adapted from Amputee Body Image Scale (Breakey, 1997)	Affective (satisfaction)
22. I am satisfied with the way my body parts look individually, but I am dissatisfied with my body when it's in motion.	"You take each part, my arm, my leg, my chest, my stomach, my back, my hair. I like all of them as individuals. When I don't like them is when I'm physically functioning out in the world, having to walk, trying to get things done."	Affective (satisfaction)
23. People make assumptions about how my body works based on how I look.	"People seeing that I'm short and I'm in a wheelchair and that automatically you know, assuming that I'm not able to do something."	FABI-O

24. People treat me differently based on how I look when I'm doing specific activities.	"You get treated differently depending on the situation and who you're interacting with and the devices you have."	FABI-O
25. My body movements probably look awkward to others.	"With my disability, my movements are just kind of awkward, and so that functioning kind of reflects on my appearance."	FABI-O
26. Society's perception of me changes when they see my body in motion.	"If you just look at me standing up, I look great I'm lookin' pretty good! If you look at me in a photograph, I'm pretty good! But when I start walkin', it all changes. Everybody's image of me changes."	FABI-O
27. Other people might think I look good in a photo, but their perception of me would change if they saw me moving about in real life.	"If you look at me in a photograph, I'm pretty good! But when I start walkin', it all changes. Everybody's image of me changes."	FABI-O
28. My relationships with others are influenced by how they see me doing specific activities.	"I've tried to like make friends with people and try to meet people. I don't know. I feel like, I feel like I can't make lasting relationships with people because I feel like people think I can't go do things or um, I don't know, I just feel like people don't give me a chance just because I'm in a wheelchair."	FABI-O
29. People notice my body's functioning when I'm out and about.	*Adapted from Amputation Body Image Scale (Breakey, 1997)	FABI-O
30. Potential romantic partners view me as less attractive when they see how my body functions.	"I've been told point blank, by men, they don't want to date me because I have a disability."	FABI-O

We organized scale items into two categories, FABI-Self (FABI-S) and FABI-Other (FABI-O). We designed FABI-S items to measure a person's thoughts and feelings about, and behaviors related to, how their body looks when it is engaged in specific functions or activities. We designed FABI-O items to measure how a person perceives *other* people think and feel about, and behaviors others might engage in related to, how the respondent's body looks when it is engaged in specific functions or activities. Initial FABI scale items generally address the three major domains of body image including the affective (satisfaction), cognitive (values), and behavioral (investment) components (Abbott & Barber, 2010).

Study One: Expert Content Validation

The purpose of Study One was to establish initial content validity of the scale items with an expert panel. We recruited 6 subject matter experts (SMEs) to review the initial FABI scale item pool, instruction set, and response options. SME panel review is a common method in scale development research (Sireci & Geisinger, 1995).

Method

Participants. We purposively recruited SMEs (N = 6) in October 2018. After obtaining IRB approval, we compiled a list of relevant experts by searching the body image, disability, and scale development literature and collecting the names and email addresses of corresponding authors. We subsequently added experts to the list based on the research team's professional contacts. Eligible participants were over the age of 18; held or had achieved candidacy for a doctoral degree in their field; considered themselves experts in the fields of body image, disability, and/or scale development; had access to the technology needed to complete the rating task; and agreed to keep the materials confidential until their publication. We initially contacted twelve SMEs. Four SMEs did not respond and two declined the invitation to participate, resulting in the final sample of six SMEs. SMEs who participated were White, female, faculty or doctoral candidates with collective expertise in body image, disability, and scale development. None of the experts identified as having disabilities.

Procedures. We obtained ethical approval prior to the start of recruitment. SMEs who agreed to participate received a link to an online survey hosted on the university's Qualtrics platform. SMEs completed an informed consent process and read the FABI construct conceptualization. This information included a summary of literature on body conceptualization theory (Alleva et al., 2014; Alleva et al., 2015; Franzoi, 1995; Mulgrew & Hennes, 2015; Mulgrew & Tiggemann, 2018); scale development rationale; and information about item development and scale construction. SMEs then rated the relevance of the 30 scale items to the FABI construct by indicating the degree to which they believed each item related to the construct on a 4-point ordinal rating scale (1= "irrelevant"; 2= "somewhat relevant/major revision needed"; 3= "quite relevant/minor" revision needed"; 4= "highly relevant"; Davis, 1992; Polit & Beck, 2006). SMEs rated whether the response options and instruction set were acceptable for the scale. SMEs had opportunities to qualitatively comment on each item, the response options, and the scale instructions. Lastly, SMEs completed demographic questions about their age, race, ethnicity, and disability status. SMEs were not incentivized.

Data analysis. SMEs completed their ratings and we closed the survey in November 2018. Quantitative data were exported from Qualtrics to IBM SPSS Statistical software Version 25 (IBM Corp., Armonk, NY) for analysis. Basic descriptive statistics were computed to determine the distribution of SME ratings. We computed the Item Content Validity Index (I-CVI) to assess item-level content validity (Polit & Beck, 2006). I-CVIs were calculated by dividing the number of SMEs who gave a rating of either 3 or 4 ("quite" or "highly" relevant, respectively) on the item by the total number of SMEs who completed ratings. We compiled experts' qualitative comments on each item, the instructions, and the response options. Two members of the research team reviewed these qualitative comments via peer debriefing (Lincoln & Guba, 1985) to guide item revision.

Results

Of the 30 items, 22 had I-CVI values greater than or equal to 0.78 (see Table 3.2). Items with I-CVI values less than 0.78 are traditionally removed from the scale following SME review (Lynn, 1986; Polit & Beck, 2006). However, after reviewing qualitative feedback, it was determined by two members of the research team that changes to item wording and structure would improve the content validity of most items. Thus, 53% of the items (including those with I-CVI values below 0.78 and some with high values) were revised in accordance with SME feedback (e.g., revising item content, providing examples within items, changing wording to better reflect the construct, etc.) and retained for testing in Study Two. We retained some items as written for Study Two (see Table 3.2). For example, Items 16 and 20 (see Table 3.2) had I-CVI levels below the 0.78 cutoff; after discussion of SME comments, we did not revise these items according to SME feedback. Item 16 related to intellectual function, which we described within the construct conceptualization provided to the SMEs as part of the definition of body functionality. Based on that and the item's relevance from the prior qualitative study, the research team opted to keep the item for the second study. Similarly, some of the content within Item 20 has been endorsed in prior research exploring barriers to physical activity among women of color (Joseph et al., 2017); given the lack of racial diversity among the SME sample, this item was retained for further testing. SMEs unanimously considered

the scale response options and instruction set adequate and commented favorably on the

scale development project as a whole.

Table 3.2. Initial item pool with SME ratings, feedback, and item revisions

Item (as worded in Study One)	SME I-CVI	Relevant SME Feedback	Item Revision
1. I worry about how I look while I am exercising or doing physical activities.	1.0	-	-
2. I am more concerned about how I look in videos of me moving (e.g., talking, laughing, walking) than how I look in still photos.	0.83	-	-
3. I dislike seeing my reflection when I'm doing an activity (e.g., walking by a glass storefront, engaged in an activity in front of a mirror).	1.0	-	-
4. I worry that my body movements look awkward.	1.0	-	-
5. The way my body looks while I'm engaged in specific activities is important to my overall sense of self.	1.0	-	-
6. I compare the way <i>my</i> body looks while doing specific activities to how <i>others</i> ' bodies look while doing those same things.	1.0	-	-
7. I make an effort with my appearance so that people will want to talk to or build relationships with me.	0.33*	So this refers to the social abilities of the body (e.g., to attract others)?	I make an effort with my appearance to overcome people's perceptions of me.
8. I am concerned that as I get older, changes in my body's functioning will affect how I look.	0.67*	Consider a broader item such as, "I am worried that any change in function (e.g., broken bone, aging, spinal cord injury) will change the way my body	I am concerned that any change in my body's functioning (e.g., hearing/ vision loss, menopause, aging, spinal cord

		looks" just to make this item relevant to more people.	injury) will affect how I look.
9. I am self-conscious about how I look when I eat.	0.83	Consider rephrasing to "I am self-conscious about the way I look during the physical act of eating, regardless of the food item" - something like that?	I am self-conscious about the way I look during the physical act of eating, regardless of the food item.
10. I am concerned about how I look when I am talking and laughing with others.	1.0	-	-
11. I worry that my appearance is worse when I feel physical symptoms (e.g., pain, exhaustion, illness).	1.0	I'd modify to "When I feel physical symptoms (e.g., pain, exhaustion, illness), I worry that my appearance is worse."	When I feel physical symptoms (e.g., pain, exhaustion, illness), I worry that my appearance looks worse
12. It is important to me that I appear as physically capable as possible.	1.0	-	-
13. I like how I look in certain clothing items when I try them on, but dislike how I look when I'm wearing them and doing activities.	0.67*	Some participants may disagree with the first part. Could rephrase to "I dislike how I look in my clothes when doing activities" - could provide examples in parentheses (e.g., walking, wheeling, exercising, sitting).	I dislike how I look in my clothes when doing activities (e.g., walking, wheeling, exercising, sitting a certain way).
14. I worry about the way others see how my body works.	0.83	I find the wording a bit awkward/difficult to understand exactly what is meant here. Perhaps, "I worry about how other people evaluate my body when they see me moving (e.g., walking, talking, eating)"?	I worry about how other people evaluate my body when they see me moving (e.g., walking, talking, eating).
15. Looking strong and functional is important to my overall sense of self.	1.0	-	-

16. I make efforts to look as smart or intellectually capable as possible.	0.33*	This item seems less immediately relevant to appearance of body function to me, though I suppose intellectual abilities can also be understood as body functions.	No change
17. I wear clothing items and/or shoes that are uncomfortable or restrict my movements because doing so helps me fit in.	0.83	I don't like "helps me fit in." Perhaps replace with "helps me look attractive."	I wear clothing items and/or shoes that are uncomfortable or restrict my movements because doing so helps me look good.
18. I engage in specific activities to prove to show others that I am physically capable.	0.67*	Perhaps "I engage in specific activities only when I know I will look acceptable doing them"?	I engage in specific activities to prove to others that I am physically capable.
19. I am concerned about how my body looks during sex.	0.83	-	-
20. The things I do to enhance my appearance (e.g., how I style my hair, the way I dress) affect the functions and activities I can do.	0.50*	Not sure how changing appearance of hair, nails, or make-up would affect function or activities? Some examples might apply but not all. Clothes totally makes sense but not all examples apply.	No change
21. Because of my body's functioning, I feel more anxious about my appearance in social situations than when I am alone.	0.67*	I wonder if it is specific to how the body functions appear to others. For example, it could also be that someone has irritable bowel syndrome, which will affect how they feel in a social context but not how their body appears to function to others from the outside.	Because of my body's functioning, I feel anxious about participating in social situations.
22. I am satisfied with the way my body parts look individually, but I am dissatisfied with my body when it's in motion.	0.33*	Consider removing the first part of the item and have only "I am dissatisfied with the way my body look	I am more satisfied with the way my body parts look individually than I

		when it's moving". With that being said, this item may be redundant to a couple items above (e.g., "I worry my body movements look awkward")	am with my body when it's in motion.
23. People make assumptions about how my body works based on how I look.	0.83	-	-
24. People treat me differently based on how I look when I'm doing specific activities.	1.0	Differently than who/what? Perhaps "The way people treat me is based on how I look when I'm doing specific activities.	The way people treat me is based on how I look when I'm doing specific activities.
25. My body movements probably look awkward to others.26. Society's perception of me changes when they see my body	0.83 1.0	Likert scale gets at the idea of "probably."	My body movements look awkward to others.
in motion.		-	-
27. Other people might think I look good in a photo, but their perception of me would change if they saw me moving about in real life.	1.0	-	-
28. My relationships with others are influenced by how they see me doing specific activities.	0.83	-	-
29. People notice my body's functioning when I'm out and about.	0.83	Perhaps "how my body moves" rather than "my body's functioning"	People notice how my body moves when I'm out and about.
30. Potential romantic partners view me as less attractive when they see how my body functions.	1.0	Perhaps "works" instead of "functions."	Potential romantic partners view me as less attractive when they see how my body works.

*Items rated below the published 0.78 cutoff *Note*. Feedback is only included for items that were revised and items that did not meet the 0.78 cutoff. Some details have been removed from SME feedback for brevity and relevance.

Discussion

Study One was a traditional scale content validation study that sought input from SMEs about 30 items designed to measure FABI. Overall, SMEs found the scale content relevant to the construct. SME qualitative feedback prompted the revision of items to retest in Study Two. A limitation to Study One was that all SMEs identified as White, female, and non-disabled. The disability status of most SMEs was not known prior to recruitment. Although we tasked SMEs only to rate whether items reflect the construct of interest, it may have been difficult for them to (or they may not have been aware of a need to) engage in "bracketing" of their biases and preconceptions (Heidegger, 1962; LeVasseur, 2003). We invited a more diverse range of scholars, including men and individuals of color, to participate, but participation rates were low. We recommend that future studies in scale development try to recruit a range of SMEs representing diverse backgrounds and to offer an incentive to improve participation rates. In line with the principles of Universal Design for Research (Williams & Moore, 2011), researchers are particularly encouraged to invite scholars with disabilities, where available, to provide subject matter expertise.

Study Two: Online Delphi Panel with Community Women

We designed Study Two as a feasibility study to test the UDM concept using a Delphi approach. The Delphi approach, originally developed by Dalkey and Helmer (1963), is a group communication process used to obtain consensus from relevant stakeholders on a given issue (Hsu & Sandford, 2007). Delphi approaches in scale development research involve multiple rounds of quantitative and/or qualitative data collection in which participants rate or comment on questionnaire items regarding their

relevance and/or importance to the subject being studied (Hsu & Sanford, 2007). Delphi panelists may also be asked to provide a rationale for their decisions about items' relevance or priority (Jacobs, 1996). Investigators analyze the data to ascertain areas of agreement between and within groups and revise the questionnaire accordingly (e.g., remove items rated differently by different groups), or re-administer the questionnaire with information about the item ratings to help foster a higher degree of consensus (e.g., display qualitative and/or quantitative data provided by first-round participants). The process has been used successfully in scale content validation, although it is typically used among subject matter experts to assess the content validity of items (Aazami & Mozafari, 2015; Colton & Hatcher, 2004). The current study presents the first known use of the Delphi approach to gain consensus on scale items from a sample of potential respondents.

We developed FABI items based on qualitative interviews from a highly specific population (e.g., women with visible physical disabilities between the ages of 18 and 55), yet the overall aim of the scale development study was to develop a universally designed FABI scale validated within the general population of women (e.g., adult women with all types of disabilities and women and without disabilities). As such, we designed this process to complement the SME panel review. Although SMEs in scale development studies possess valuable content-related and methodological expertise, they may not possess the insight necessary to judge whether items would be equally relevant to, or perceived the same way by, women representing a range of abilities and other characteristics. Therefore, in Study Two, we pilot-tested an online Delphi process to assess and gain consensus about the relevance and importance of the scale items among community women representing a range of backgrounds including disability,

race/ethnicity, and age to facilitate the development of a FABI scale applicable to a broad range of women.

Method

Participants. We recruited participants (N = 33) in November 2018. This sample size was deemed acceptable in accordance with previously published guidelines for Delphi panel studies (Ludwig, 1997; Witkin & Altschuld, 1995). After obtaining ethical approval, we created a Facebook post to recruit participants from the first author's personal contacts. We purposively recruited participants to maximize retention between iterations of the Delphi process. Initially, 18 participants identified as having a disability and 15 identified as non-disabled. Participants who completed both rounds of the Delphi survey received a \$10 Amazon.com e-gift card after Round 2.

Procedures.

Eligibility survey. Interested individuals accessed a link to the online survey hosted on the university's Qualtrics platform. Participants completed the initial informed consent process and then responded to eligibility questions to confirm that they met the study's inclusion criteria (e.g., they were over the age of 18; identified as women in a way that was meaningful to them; could express themselves in written English; had access to the technology needed to complete the survey; and committed to participating in both rounds of the Delphi process within an approximate four-week time span). They also completed basic demographic questions (e.g., race, ethnicity, and disability status) so that investigators could ensure representation from women with and without disabilities and attempt to maximize inclusion of individuals from other diverse backgrounds. Lastly,

participants provided their email addresses so they could be contacted for the Delphi panel. A total of 52 people completed the eligibility survey. All who completed the survey were eligible for the study and were contacted to join the study.

Round 1. All eligible participants received a link to the Round 1 survey on December 10th, 2018. Participants engaged in a second informed consent process and were directed to the rating task. Participants rated each of the revised 30 scale items according to their relevance to their personal experience with body image. Participants made ratings on a Likert-type scale ranging from 1 ("not relevant to me") to 4 ("highly relevant to me"). Participants also completed a brief demographic questionnaire. We closed the Round 1 survey on December 20th, 2018.

Round 2. We emailed a link to the Round 2 survey to participants on January 10th, 2019. The Round 2 survey was split into two tasks. First, we listed all scale items along with information about how participants rated them in Round 1 (e.g., the percentage of respondents who rated the item at least "somewhat relevant," and selected qualitative comments from Round 1 participants explaining their ratings). After reading this information, participants rated the scale items again; this time they were prompted to rate them on the same Likert scale according to how important they thought the items were to women's overall body image.

In the second task, we asked participants to rank order the items according to their perceived importance to women's overall body image. We designed this ranking procedure to provide another metric, if needed, to facilitate the final process of eliminating or revising scale items (e.g., if items were consistently rated as unimportant, they might be removed from the scale). We grouped items according to their domain (i.e., affective, behavioral, and cognitive items on the FABI-S scale were each grouped and ranked separately, and FABI-O items were ranked separately) to facilitate the ranking process.

Data analysis. Data collected from all Delphi surveys was exported from Qualtrics and imported to SPSS version 25 (IBM; Armonk, NY) for analysis.

Round 1 data analysis. We first assessed sample demographics by conducting basic descriptive analyses. The percentage of respondents who rated the items at least "somewhat relevant" was computed to include in the Round 2 survey to facilitate the consensus-building process. Qualitative comments were also included in the Round 2 survey. We conducted independent t-tests to determine whether women with disabilities rated items differently than women without disabilities. Due to the small and slightly different group sample sizes, we used Hedges' *g* to assess the magnitude of such between-group differences (Hedges, 1981); published guidelines were used to interpret *g* values (i.e., small effects < 0.2, medium effects 0.2 to 0.5, and large effects > 0.5; Cohen, 1988).

Round 2 data analysis. After Round 2, we assessed participant completion of both rounds of the Delphi process. Independent t-tests were computed; Hedges' *g* was again used to assess the magnitude of between-group differences. Participants' rankings of items under each domain were assessed using Friedman's test.

Results

Participants. Participants ($M_{age} = 39.5$; $SD_{age} = 14.7$) were 72.7% White; 9.1% Black or African American; 6.1% Asian or Pacific Islander; 6.1% Native American or Alaska Native; and 6.1% more than one race. Approximately 12% identified as Hispanic or Latinx. Regarding educational attainment, 45.5% of the sample had a bachelor's or 4year degree; 27.3% had a master's degree; 9.1% had a doctoral or other professional degree; 9.1% completed some college; 6.1% attained a GED or high school diploma; and 3% had an associate's or 2-year degree. Approximately 94% of participants who completed Round 1 also completed Round 2, indicating good retention. Participants who dropped out represented both study groups (i.e., one woman had a disability and the other did not). Round 2 results are based on a sample size of 31. Of the 31 participants that completed Round 2, two stopped the survey before completing the rank ordering task; therefore, the Friedman's test results are based on a sample size of 29.

Item ratings. Independent t-tests conducted after Round 1 indicated that the magnitude of between-group differences varied widely across the pool of items (*g* values ranged from .04 to 1.39; see Table 3.3). After providing controlled feedback in Round 2, *g* values decreased or stayed the same for 23 items; whereas effect sizes increased for Items 2, 13, 15, 16, 18, 19, and 22. Eleven items were determined to have fully met consensus (i.e., had effect sizes less than .20 after Round 2), and seven items had effect sizes between .2 and .3 indicating a low to medium magnitude of difference between groups.

Item rankings. Friedman's tests revealed the mean rank for each item (see Table 3.4). Higher mean ranks in each domain correspond to ratings of lower importance. Items 9, 14, and 22 had the highest mean ranks in the Affective domain; Items 17 and 20 had the highest mean ranks in the Behavioral domain; Item 5 had the highest mean rank in the Cognitive domain; and Items 28, 29, and 30 had the highest mean ranks in the FABI-O domain.

	Delphi Round 1		Delphi Round 2	
Item (as worded in Study Two)	Mean difference	Hedges' g	Mean difference	Hedges' g
1. I worry about how I look while I am exercising or doing physical activities.	30	31	20	24
2. I am more concerned about how I look				
in videos of me moving (e.g., talking, laughing walking) than how I look in	06	04	39	40
still photos.				
3. I dislike seeing my reflection when I'm				
doing an activity (e.g., walking by a glass storefront engaged in an activity in front	.24	.20	.18	.20
of a mirror).				
4. I worry that my body movements look	.38	.36	.13	15
awkward. 5 The way my body looks while I'm				
engaged in specific activities is important	22	19	07	07
to my overall sense of self.				
6. I compare the way my body looks while doing specific activities to how				
others' bodies look while doing those	71	63	31	61
same activities.				
7. I make an effort with my appearance to	.66	.57	.18	.24
8. I am concerned that any change in my				
body's functioning (e.g., hearing/vision	51	44	09	11
loss, menopause, aging, spinal cord			.09	
9. I am self-conscious about the way I				
look during the physical act of eating,	.17	.15	.15	.16
regardless of the food item.				
when I am talking and laughing with	.63	.81	.18	.19
others.	100	101		,
11. When I feel physical symptoms (e.g.,	116	1.24	0.6	05
appearance looks worse	1.10	1.34	.06	.05
12. It is important to me that I appear as	70	62	22	26
physically capable as possible.	.70	.02	.22	.20
13. I dislike how I look in my clothes when doing activities (e.g. walking				
wheeling, exercising, sitting a certain	07	06	32	35
way).				
14. I worry about how other people	24	21	12	16
moving (e.g., walking, talking, eating).	.24	. 41	.14	.10

Table 3.3. Magnitude of between-group differences in Rounds 1 and 2 of the Delphi panel

15. Looking strong and functional is important to my overall sense of self	.14	.15	.21	.34
16. I make efforts to look as smart or	07	0.4	20	25
intellectually capable as possible.	06	04	28	35
17. I wear clothing items and/or shoes				
that are uncomfortable or restrict my	76	90	77	90
movements because doing so helps me	., 0	.,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,,	.,,	.,,,
look good.				
18. I engage in specific activities to prove	12	12	38	45
to others that I am physically capable.				
19. I am concerned about how my body	16	14	32	37
20. The things I do to enhance my				
20. The unitigs I do to eminance my				
way I dress) affect the functions and	.29	.26	.14	.14
activities I can do				
21. Because of my body's functioning. I				
feel anxious about participating in social	.30	.26	.26	.26
situations.				
22. I am more satisfied with the way my				
body parts look individually than I am	31	30	43	46
with my body when it's in motion.				
23. People make assumptions about how	1 16	1.08	25	31
my body works based on how I look.	1.10	1.00	.23	.51
24. The way people treat me is based on				
how I look when I'm doing specific	.58	.65	.39	.44
activities.				
25. My body movements look awkward	.29	.38	.13	.14
to others.				
20. Society's perception of the changes	.54	.51	.24	.27
27 Other people might think Llook good				
in a photo, but their perception of me				
would change if they saw me moving	04	04	03	02
about in real life.				
28. My relationships with others are				
influenced by how they see me doing	.40	.56	.26	.32
specific activities.				
29. People notice how my body moves	20	30	05	05
when I'm out and about.	.29	.30	.05	.05
30. Potential romantic partners view me				
as less attractive when they see how my	.60	.58	06	06
body works.				

Note. Negative mean differences indicate women without disabilities had higher mean rating than women with disabilities.

Table 3.4. Results of Friedman's test of rank-ordered items

Item and domain	Mean rank
Affective	Tunix
1 I worry about how I look while I am exercising or doing physical activities	3 72
2. I am more concerned about how I look in videos of me moving (e.g., talking,	4.72
laughing, walking) than how I look in still photos.	
3. I dislike seeing my reflection when I'm doing an activity (e.g., walking by a glass	5.41
storefront, engaged in an activity in front of a mirror).	
19. I am concerned about how my body looks during sex.	6.38
10. I am concerned about how I look when I am talking and laughing with others.	6.55
4. I worry that my body movements look awkward.	6.59
13. I dislike how I look in my clothes when doing activities (e.g., walking, wheeling,	6.90
exercising, sitting a certain way).	
8. I am concerned that any change in my body's functioning (e.g., hearing/vision	7.00
11 When I feel physical symptoms (e.g. pain exhaustion illness) I worry that my	7 59
appearance looks worse	1.57
21 Because of my body's functioning. I feel anxious about participating in social	8 66
situations	0.00
14 I worry about how other people evaluate my body when they see me moving	872
(e g walking talking eating)	0.72
9 I am self-conscious about the way I look during the physical act of eating	8 86
regardless of the food item	0.00
22 I am more satisfied with the way my body parts look individually than I am with	9 90
my body when it's in motion	<i></i>
ing oody when it is in motion.	
Behavioral	
7. I make an effort with my appearance to overcome people's perceptions of me.	2.07
6. I compare the way my body looks while doing specific activities to how others'	2.59
bodies look while doing those same activities.	
16. I make efforts to look as smart or intellectually capable as possible.	3.00
18. I engage in specific activities to prove to others that I am physically capable.	3.86
17. I wear clothing items and/or shoes that are uncomfortable or restrict my	4.66
movements because doing so helps me look good.	
20. The things I do to enhance my appearance (e.g., how I style my hair, the way I	4.83
dress) affect the functions and activities I can do.	
Cognitive	1 60
15. Looking strong and functional is important to my overall sense of self.	1.69
12. It is important to me that I appear as physically capable as possible.	1.83
5. The way my body looks while I'm engaged in specific activities is important to my	2.48
overall sense of self.	
7ADI-U 22 Deeple make accumptions shout how my hady works haved on how Llock	2.02
25. reopte make assumptions about now my body works based on now 1 look.	∠.03 2.72
24. The way people treat me is based on now I look when I m doing specific	3.12
activities. 27 Other people might think I look good in a photo, but their perception of me	131
27. Other people might mink i look good in a photo, but their perception of me	4.34
would change if they saw me moving about in real me.	

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26. Society's perception of me changes when they see my body in motion.	4.52
25. My body movements look awkward to others.	4.93
29. People notice how my body moves when I'm out and about.	5.34
30. Potential romantic partners view me as less attractive when they see how my	5.48
body works.	
28. My relationships with others are influenced by how they see me doing specific	5.62
activities.	

Discussion

Study Two served as a pilot test of the UDM concept. We implemented a tworound Delphi study to assess consensus about scale items among women with and without disabilities. In Round 1, we asked participants to rate the relevance of the items to their personal experiences with body image. Ratings for several items differed among the two groups. It is important to note, though, that despite generating the scale items from qualitative interviews with women with disabilities, women without disabilities rated many of the items as more relevant and important than did women with disabilities. For example, of the 12 items with effect sizes above .30 after Round 2 of the Delphi panel, 8 were rated higher by women without disabilities, suggesting the FABI construct overall is not specific to women with disabilities, but rather endorsed by women with a range of abilities.

Hedges' *g* decreased for most items after Round 2, supporting the use of the Delphi process as a promising approach toward gaining consensus about scale items and therefore creating a universally designed measure. Due to resource limitations, we only conducted two rounds in the Delphi study. Future research may explore conducting additional rounds to retest items or prompt participants to further explain their ratings. We could also revise items between rounds in the future, resulting in more robust explorations of the UDM concept.

Overall, results suggest that the two groups of women rated many items similarly: 61.5% of items in the Affective domain, 66.7% of items on the Cognitive domain, and 62.5% of items in the FABI-O domain reached consensus. Interestingly, only 33.3% of items in the Behavioral domain reached consensus. We hypothesize that these items may differ between groups because they relate to self-presentation (Leary & Kowalski, 1990), or "impression management." The propensity for individuals with disabilities to endorse perfectionistic self-presentation and engage in impression management behaviors to reduce stigma and discrimination is documented and may not be as applicable to those without disabilities (Bailey, Gammage, van Ingen, & Ditor, 2016; Read, Hill, Jowett, & Astill, 2019; Sung, Lin, Connor, & Chan, 2017).

Limitations of Study Two are that the sample was purposively recruited, and we did not measure participants' overall body image orientation. Future researchers employing the Delphi technique in scale development research should assess a baseline level of the construct of interest. For example, the eligibility survey might have included a measure of overall body image (e.g., the Multidimensional Body Self Relations Questionnaire; Brown, Cash, & Mikulka, 1990; Cash, 2018) or even a single, self-report item assessment ("how would you rate your overall body image?") to facilitate controlling for body image in the analyses.

Retention between Delphi rounds was acceptable. However, only about 63% of people who were eligible and emailed to participate eventually joined the Delphi study. Those who participated in the Delphi study did not differ demographically from the entire sample of those who were eligible. People may have lost interest in the study during the short time between the eligibility survey and contact for the Round 1 survey. Still, the response rate was high for an online survey study (Nulty, 2008).

Overall Discussion

This purpose of this research was to establish content validity of a set of items designed to measure functional-aesthetic body image among women *with and without* disabilities. The studies demonstrate the potential of the UDM framework for developing measurement tools validated in broad populations to minimize the need for scale revision and adaptation. Study findings illuminate strengths of the UDM concept and considerations for its further development.

In combination, Studies One and Two provide several valuable metrics to guide item retention and deletion decisions for the final scale. Two scale items consistently failed to meet established cutoff values in both studies, indicating that they may perform inadequately in future studies using the FABI scale. For example, Items 18 and 22 may be problematic, given that they did not meet the SME rating threshold for content validity in Study One, moved *away* from consensus during the Delphi process, and participants ranked them least important of the Affective domain items in Study Two. We could remove or revise items considered problematic as determined by all or most available metrics from the scale prior to conducting the next phase of study (e.g., factor analysis, pilot-testing, etc.).

Participants rated some items inconsistently across the two studies. Items 7, 8, and 21, for example, did not meet the I-CVI threshold in Study One, but performed well in Study Two. These results may be partially explained by the fact that these items were revised based on SME feedback in Study One before conducting Study Two. This finding

emphasizes the importance of collecting *qualitative* feedback from SMEs to guide item revision, rather than simply deleting items that fail to meet published quantitative cutoffs (Lynn, 1986; Polit & Beck, 2006).

Conversely, Items 2, 15, and 19 met the I-CVI threshold but still had medium to large between-group effect sizes after Round 2 of the Delphi panel and moved away from consensus during the process. This finding provides preliminary evidence supporting the testing of scale items among a diverse sample of potential test-takers *with lived experience* (in this case, community women with and without disabilities) in addition to conducting the SME panel study. The process may be particularly valuable in studies of emerging constructs for which there is not a strong empirical evidence base. It may also provide value in studies addressing a topic that transcends specific disciplines (e.g., body image and disability) where individuals with subject matter expertise in both or multiple related disciplines, and/or those who are representative of the groups of which researchers are trying to be inclusive, may be few and far between.

Universal Design for Measurement: Guidelines for Implementation

Study findings prompted the expansion of the Universal Design for Research framework proposed by Williams and Moore (2011) to more thoughtfully address the need for measurement instruments validated for use among people with disabilities that are not designed *only* for use in this population. The resulting UDM framework encourages researchers to: (a) derive scale items from qualitative data generated from studies focusing on (or at least including an appreciable sample of) people with disabilities to center their experiences; (b) intentionally include people with disabilities and collect disability demographic data from in all scale validation studies unless there is a compelling scientific rationale for not doing so; (c) thoughtfully balance qualitative and quantitative data about content validity from SMEs with that of those with disabilities/lived experience, particularly when it is known that SMEs do not have experience with disability; and (d) conduct as many rounds of consensus building among people with and without disabilities as is feasible given study resources. These recommendations will allow for more effective comparisons of health indicators between people with and without disabilities and promote stronger measurement science.

Implications for Disability Researchers

Disability health disparities may be difficult to quantify when people with disabilities are not included in mainstream health research and when their health status, behaviors, and outcomes are assessed using separate or modified measures (Teresi, Ramirez, Jones, Choi, & Crane, 2012). The UDM framework is useful for disability researchers who want to develop measures of common health and social constructs that can be used in mixed-ability populations, including populations with different types of disabilities. Scales designed using the UDM framework might also be useful in comparing results of multiple studies measuring the same construct across populations, as it minimizes the need for scale modification, which can present challenges to accurate comparison.

It is also important to note that the UDM framework can support the adaptation of existing measures. Previously developed measures that have not been validated but seem to be appropriate for use within mixed-ability populations can be piloted using the online Delphi technique prior to their use. Researchers can also conduct adaptation studies by conducting cognitive interviews (Peterson, Peterson, & Powell, 2017; Willis, 2005) about existing measures with people with disabilities, then implementing the Delphi process with a revised scale.

Measurement Implications

Although the present research focuses on the inclusion of individuals with disabilities within the scale development and validation process, the UDM framework has the potential to be used to address the inclusion of other minority populations, for example sexual minorities, in measurement research (Bettinger, 2010). When working in hard-to-reach populations, many scholars use scales that have not been validated in the population of interest by modifying certain scale items, and then provide internal consistency reliability metrics to suggest that the scale performed adequately. Although internal consistency is important, coefficient alpha does not suggest validity of a measurement instrument (Schmitt, 1996). Researchers working in hard-to-reach populations and those involved in the design and validation of measurement instruments should consider adopting the UDM guidelines to ensure measurement tools are widely validated and used appropriately.

The UDM framework demonstrated in the present study may also be an effective approach to preventing measurement invariance issues. Measurement invariance assumes that a set of items equivalently measures a latent variable across different demographic groups (e.g., gender or socioeconomic groups; Meredith, 1993). Scholars have reported several methods to *detect* non-invariant items (De Roover, Timmerman, De Leersnyder, Mesquita, & Ceulemans, 2014; Meredith, 1993; Meredith & Teresi, 2006), which are typically performed at the confirmatory factor analysis stage. However, the literature describing ways to *promote* measurement invariance during the scale development phase is underdeveloped. Assessing consensus between groups about a set of items before test administration and factor analyses may reveal items that may later be found noninvariant. More research is needed to assess the ability of the UDM approach to address measurement invariance concerns.

Limitations and Future Directions

The overall approach to scale development described in this manuscript is subject to limitations beyond those mentioned in relation to each study. The research was exploratory in nature; therefore, its results should be interpreted with some caution. First, despite attempts to recruit diverse participants in both studies, the samples were limited in racial/ethnic diversity, although age, disability, and educational attainment varied. A related limitation is that due to the limited diversity across other demographic characteristics, only between-group differences on the FABI items regarding disability status were assessed. Differences between racial/ethnic and age groups, for example, may be important to explore in future demonstrations. For scales to be considered truly "universal," we recommend that future studies using the UDM framework incorporate as many facets of identity as are relevant to the construct of study.

We also encourage researchers to conduct more robust studies exploring the utility of the UDM concept. The present study was resource-limited, preventing the research team from conducting additional rounds of the consensus-building process. Designs in which SMEs are *incorporated* within the Delphi process along with individuals with lived experience, which might prevent the need to conduct multiple studies, should be explored. Lastly, we encourage researchers implementing to determine relevant criteria upon which they will base item retention decisions. For example, for
studies of constructs with a well-developed evidence base, it may prove logical to rely on SME feedback; however, for studies of newly-emerging constructs, emphasis might be placed on the ratings of people with lived experience, as they may be the only "experts" on the topic at that time. Researchers might also consider conducting exploratory factor analyses to confirm item retention decisions.

Conclusion

This study aimed to demonstrate proof-of-concept for UDM. Findings suggest this framework has the potential to further promote the inclusion of individuals with disabilities within mainstream health research by offering a flexible approach to developing measurement instruments that are relevant to people with disabilities' experiences and are also appropriate for use within the general population. UDM is a practical approach that makes a significant contribution toward effectively quantifying and addressing disability and other minority health disparities.

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CHAPTER 4: PSYCHOMETRIC ANALYSIS AND INITIAL VALIDATION OF THE FUNCTIONAL-AESTHETIC BODY IMAGE SCALE

Abstract: The construct of body functionality is accumulating increased attention among body image researchers. Body functionality was previously considered a facet of positive body image; however, recent qualitative scholarship investigating body functionality and appearance among women with visible physical disabilities suggests that women may also experience body functionality as an aspect of negative body image, particularly when it overlaps with concerns about their appearance. "Functional-aesthetic body image" is the construct that describes this intersection of appearance and functionality. The purpose of this study was to psychometrically evaluate and validate the newly developed Functional-Aesthetic Body Image (FABI) scale among a sample of 285 community women with and without disabilities (ns = 137 and 148, respectively). Exploratory factor analysis revealed a four-factor structure with 22 items. Correlational and regression analyses provide evidence for the scale's internal consistency and convergent, discriminant, and incremental validity. Findings highlight the validity and utility of the FABI scale and offer unique insights regarding the measurement of body image variables with mixed-ability populations.

Introduction

Body functionality is defined as all the things the body can and cannot do, including its physical, cognitive, social, and emotional processes (Alleva, Tylka, & Kroon Van Diest, 2017; Vinoski Thomas et al., 2019). This contemporary definition of body functionality has evolved through decades of scholarship initially emphasizing the physical condition (Franzoi & Shields, 1984) and later expanding to include the body's physical and mental skills, its health and internal processes, creative endeavors, self-care, and the ways in which the body interacts with other bodies (Alleva, Martijn, Jansen, & Nederkoorn, 2014; Alleva, Martijn, VanBreukelen, Jansen, & Karos, 2015; Alleva, Veldhuis, & Martijn, 2016; Alleva, Tylka, & Kroon Van Diest, 2017; Avalos & Tylka, 2006). Body functionality has emerged as an important construct in body image research.

Body conceptualization theory (BCT; Franzoi, 1995) supports the study of body functionality as a component of body image. The theory suggests that individuals appraise their bodies either in terms of their appearance ("body-as-object") or their capabilities ("body-as-process"; Franzoi, 1995). Empirical research rooted in BCT suggests that training women to focus on their body functionality over their appearance may promote body appreciation, thus reducing some of the negative effects of viewing thin-ideal media (e.g., self-objectification), a primary driver of body image concerns (Alleva et al., 2014; Alleva et al., 2015; Alleva et al., 2016; Stern & Engeln, 2018). Researchers consider body functionality a component of positive body image. This line of research is promising, but has not yet encompassed some of the complexities related to BCT under exploration within emerging science. For example, scholars considered whether body functionality, particularly as it was originally defined, would be exclusive of individuals with disabilities or who have other disruptions in body function (Webb, Wood-Barcalow, & Tylka, 2015). Two studies to date have explored the concept of body functionality among women with a range of disabilities, with varying results. One study explored how participation in a bodyfunctionality focused writing intervention affected body image outcomes among women with rheumatoid arthritis, who reported experiencing alterations in their body functionality and appearance because of their rheumatic condition (Alleva et al., 2018). The study found that women with rheumatoid arthritis experienced enhanced functionality appreciation, body appreciation, body satisfaction, and body-self alienation, and reduced depression, as a result of intervention participation (Alleva et al., 2018). This study provides evidence that even with functional limitations, people with rheumatoid conditions can positively experience body functionality.

Another study explored body functionality and appearance themes qualitatively among women with visible physical disabilities (Vinoski Thomas et al., 2019). The study found that women with visible physical disabilities considered body functionality an integral part of their body image, and that it was associated with both positive *and negative* body image (Vinoski Thomas et al., 2019). The study supported expanding the definition of body functionality used within body image research to also include negative aspects (i.e., things the body *cannot* do). From this study also emerged a novel body image construct, "functional-aesthetic body image" (FABI), which describes the intersection of appearance and function. Participants described evaluating their bodies in terms of their appearance *while* engaging in specific body functions, suggesting that the domains of function and appearance are not as separate as previously conceptualized (Vinoski Thomas et al., 2019; Franzoi, 1995). FABI is the focus of the present study.

FABI overlaps with, yet is conceptually distinct from, constructs offered in extant scholarship. For example, Webb and colleagues (2017a; 2017b) discussed "objectified body competence," or the convolution of media messages emphasizing physical body competence with media messages underscoring appearance. These studies found evidence that women are often represented engaging in active yoga poses while simultaneously posed and/or outfitted in an objectified manner (e.g., with high levels of skin exposure and outfitted in tight clothing; Webb et al., 2017a; 2017b). The authors concluded that media messages that fuse physical body competence with a focus on how the body appears may be particularly harmful to women's overall body image (Webb et al., 2017a; 2017b). Although objectified body competence also addresses the intersection of body functionality and appearance themes, FABI has a broader functionality focus – it is derived from a holistic definition of body functionality and therefore encompasses social and intellectual functioning in addition to the physical condition.

The Embodied Image Scale (EIS; Abbott & Barber, 2010) also integrates function into body image; however, it does so by incorporating two separate subscales measuring functionality and aesthetics, rather than measuring one construct reflective of a blend between form and function. Items included in the EIS Function subscale also have a strong focus on physicality; e.g., "How good I feel about my body depends a lot on what my body can do physically," "I do physically active things often (e.g., sports, hiking, exercise)," and "I am very happy with my performance in physical activities" (Abbott & Barber, 2010), and thus may be less reflective of the more comprehensive definition of body functionality currently accepted in the literature (Alleva et al., 2017; Vinoski Thomas et al., 2019).

Lastly, the Situational Inventory of Body Image Dysphoria (SIBID; Cash, 1994a, 2002) contains several items that overlap with FABI concepts. The instrument asks participants to indicate how often they have negative feelings or emotions about their physical appearance in various specific situations, including: "At social gatherings where I know few people," "When anticipating or having sexual relations," "When I see myself in a photograph or videotape," and "During certain recreational activities." Some of these items overlap considerably with functional domains; therefore, there are overlaps with FABI scale items. However, there are important distinctions between these constructs and their scales. While SIBID is concerned with the broad situational *contexts* in which people experience negative body image, FABI is concerned with the specific *functions* a person is engaging in within those contexts. Similarly, SIBID addresses only emotional reactions related to the various situational contexts it addresses (Cash, 2002), whereas FABI items are also designed to measure cognitive-behavioral investment in one's functional-aesthetics and perceptions of how others view the body when it is engaged in functions.

FABI Scale Development

We derived FABI scale items from qualitative interviews with women with visible physical disabilities (Vinoski Thomas et al., 2019) and extant empirical research (Asai, Kanayama, Imaizumi, Kyama, & Kaganoi, 2016; Breakey, 1997; Suendermann, Rydberg, Linder, & Linton, 2018). We originally organized items into two categories: FABI-S items measure a person's thoughts, feelings, and behaviors related to how their body looks when it is engaged in specific functions or activities. FABI-O items measure a person's perceptions about how other people think and feel about, and behaviors they might engage in regarding, how the subject's body looks when it is functioning. FABI-S items ultimately address the three major domains of body image including the affective, cognitive, and behavioral components (Abbott & Barber, 2010).

Subject matter experts (SMEs) reviewed the item pool, instructions, format, and response options (Dissertation Manuscript 2). We revised items according to SME feedback and then reviewed by community women with and without disabilities using a Delphi process. We recruited this sample to assess the universal applicability of the scale items to women across disability status (Dissertation Manuscript 2). In this way, the FABI scale items can be considered "universally designed." We conducted these prior studies to test the content validity and universality of scale items; the studies resulted in a series of metrics we used to guide item retention decisions described in this paper.

The Present Study

It would be useful for researchers exploring the intersection of body functionality and appearance have access to a measure of this concept; yet there are no published instruments assessing an equivalent construct. Therefore, the aims of this study were to pilot the FABI scale among a sample of community women with and without disabilities, and evaluate its factor structure and criterion-related validity.

We hypothesized that, given the design of the scale (Vinoski Thomas et al., 2019; Dissertation Manuscript 2), the exploratory factor analysis (EFA) of the FABI scale would produce a four-factor solution, with items loading on affective, behavioral, cognitive, and FABI-O domains (H1). We also expected that analyses of retained FABI items following the EFA would support the internal consistency of the full scale and any domains that emerged in the full sample and across groups stratified by disability status (H2).

The next set of hypotheses address the scale's psychometric properties. We hypothesized that FABI scale scores would be positively correlated with scores on a measure of functional disability (WHODAS) and measures of negative body image (i.e., appearance orientation [AO], situational body image dysphoria [SIBID-S], and body image disturbance [BIDQ]) and negatively correlated with measures of positive body image (i.e., functionality appreciation [FAS] and body compassion [BCS]) and body satisfaction (appearance evaluation [AE]) to provide evidence for convergent validity, and that FABI would be negatively correlated with a measure of self-esteem (SISE), providing evidence for discriminant validity (H3). We expected the strength and directionality of these correlations to be similar among women with and without disabilities (H4). Table 4.1 shows the expected correlational directionality between FABI and other measured variables.

Measure	Expected direction of
	correlation with FABI
WHODAS	+
FAS	-
BIDQ	+
AE	-
AO	+
SIBID-S	+
BCS	-
SISE	-

Table 4.1. Expected correlations between FABI and other study variables

The last two hypotheses focus on the scale's incremental validity. We

hypothesized finding, through two separate hierarchical regression models, that FABI

would be evaluated as a unique construct accounting for additional variance in body image disturbance scores beyond the variance predicted by functional disability and appearance evaluation (H5), and that FABI would account for *more* variance in body image disturbance scores (beyond other measures of functionality and appearance) than the measure of situational body image dysphoria, providing evidence of incremental validity (H6).

Method

Participants and Procedure

The UNC Charlotte Institutional Review Board approved this study. We recruited participants from Amazon Mechanical Turk (MTurk), a participant pool website. On MTurk, individuals register as "workers" to complete brief tasks or "HITs" in exchange for small amounts of money (Buhrmester, Kwang, & Gosling, 2011). Numerous scale validation studies, including those in the field of body image (Alleva et al., 2017; Gardner, Brown, & Boice, 2012), have used the MTurk participant pool.

Eligible participants were women who identified as women in a way that was meaningful to them, were 18 years of age or older, and could express themselves using Standard English. We recruited individuals to participate in a study about "body image and health" and provided them a brief description of the eligibility criteria. We noted in the study description that we were particularly interested in responses from women who identified as having disabilities; for the purposes of this study, "disability" referred to physical/mobility disabilities, developmental disabilities, learning disabilities, mental health conditions, chronic medical conditions, or any other health condition the individual personally identified as a disability. We set a quota so that roughly half of the sample would identify as having some type of disability and half would not.

The survey was hosted on the university's Qualtrics platform and linked via MTurk. Participants who accessed the survey read through an informed consent page. They completed eligibility questions and demographic items first to assess eligibility and then to provide their disability status for the quota. When the quota filled, ineligible participants were bumped out of the survey and instructed to return the HIT so that it became accessible to eligible workers. All *eligible* participants then completed the FABI scale first; we showed all other scales in a random order to control for order effects. Participants received \$0.50 for survey completion, in line with MTurk guidelines.

We excluded participants from the dataset if they had more than 40% missing data (n = 6), or if they failed at least one of three attention check questions (n = 9) placed throughout the survey. These adjustments resulted in an analytic sample of N = 285 (n_{with} disabilities = 137; $n_{without disabilities} = 148$). Analysis of worker identification numbers in the payment process confirmed that no participants completed the survey more than once.

Women included in the final sample ranged in age from 18 to 73 (M = 33.27, SD = 11.13) years. Among the 48% of the sample that identified as having at least one type of disability, 51.1% had a mental health disability, 30.7% had a chronic medical condition, 19.7% had a physical or mobility disability, 18.3% had a vision or hearing disability, 9.5% had an intellectual or developmental disability, 6.6% had a learning disability, and 3.7% indicated they had some other type of disability. Self-reported body mass index (BMI) was similar between women with and without disabilities (M_{with} disabilities = 26.21, SD = 6.89; $M_{\text{without disabilities}} = 26.47$, SD = 6.89). The sample was

predominately White (73.7%). Black women and Asian women each comprised another 7.7% of the sample; Latina/x women comprised 3.2%, Native American/Alaska Native women comprised 2.8%, and individuals of multiple races or who identified as another race comprised the remaining 1.1%. Educational attainment varied; 14.1% attained a high school diploma, GED, or less; 20.7% completed some college; 9.1% attained a two-year degree; 41.8% attained a four-year degree; and 14.4% attained a master's, doctoral, or other professional degree (e.g., JD). The distribution of race (p = .65) and educational attainment (p = .17) did not significantly differ between groups.

Measures

Demographic items. Participants completed questions regarding their age, race/ethnicity, self-reported current height and weight (to calculate BMI), highest level of education completed, and disability status and type.

Functional Aesthetic Body Image Scale (FABI; Dissertation Manuscript 2).

Participants completed the 30-item version of the Functional Aesthetic Body Image scale (Dissertation Manuscript 2). The items cover multiple domains of body image (e.g., affective, behavioral, etc.). Sample items include, "I am self-conscious about the way I look during the physical act of eating or drinking, regardless of the food item or beverage," and "It is important to me that I appear as physically capable as possible." Participants rated items on a scale of 1 (strongly disagree) to 5 (strongly agree). We averaged scores on the overall scale and the subscales using the retained items; higher scores therefore indicate greater functional-aesthetic body image disturbance.

World Health Organization Disability Assessment Schedule 2.0, short, selfadministered version (WHODAS; Üstün, T. B., & World Health Organization [WHO], 2010). The WHODAS is a 12-item measure of functional disability across six functional domains, including cognition (e.g., concentrating, learning); mobility (e.g., standing, walking long distances); self-care (e.g., hygiene, dressing); getting along (e.g., interacting with strangers, maintaining friendships); life activities (e.g., day-to-day activities such as domestic responsibilities, work); and participation (e.g., engagement in community activities in the same way as others, emotional effects of health concerns). Participants are asked how much difficulty they have had with the various activities in the past 30 days and respond on a 5-point Likert scale ranging from 0 (none) to 4 (extreme or cannot do). Scores are summed; higher scores reflect a higher degree of disability. The 12-item version explains 81% of the variance of the full 36-item version (Üstün & WHO, 2010). Previous validation studies suggest that the 12-item self-administered version shows good internal consistency reliability ($\alpha = .83$ -.92) and high 2-week test-retest reliability (intraclass correlation coefficient = .83) in online administration (Axelsson, Lindsäter, Ljótsson, Andersson, & Hedman-Lagerlöf, 2017). Cronbach's alpha for the present study was .92 (.90 for women with disabilities, .92 for women without disabilities).

Functionality Appreciation Scale (FAS; Alleva et al., 2017). The FAS is a 7item measure of a person's appreciation for their body's functionality. Sample items include, "I am grateful for the health of my body, even if it isn't always as healthy as I would like it to be," and "I respect my body for the functions that it performs." Participants rate items from 1 (strongly disagree) to 5 (strongly agree). Scores are averaged, with higher scores reflecting higher levels of functionality appreciation. FAS scores have shown good internal consistency ($\alpha = .88$ for women), construct validity, and 3-week test-retest reliability in US adult women (Alleva et al., 2017). The scale has also shown good internal consistency ($\alpha = .90$) in a sample of women with varying levels of rheumatic disability (Alleva et al., 2018). In the present study, Cronbach's alpha was .90 (.87 for women with disabilities, .93 for women without disabilities).

Appearance Evaluation subscale of the Multidimensional Body-Self Relations Ouestionnaire (MBSRO; Brown, Cash, & Mikulka, 1990; Cash, 2018). The

Appearance Evaluation (AE) subscale is a 7-item measure of one's feelings of physical attractiveness and satisfaction with appearance. Sample items include, "I like my looks just the way they are," and "Most people would consider me good-looking." Participants respond on a 5-point scale ranging from 1 (definitely disagree) to 5 (definitely agree). Scores are averaged, with higher scores indicating greater appearance satisfaction. Scores demonstrate internal consistency, construct validity, and good 1-month test-retest reliability in US adult women (Cash, 2018). In the present study, Cronbach's alpha was .90 (.86 for women with disabilities, .92 for women without disabilities).

Appearance Orientation subscale of the MBSRQ (Brown, Cash, & Mikulka, 1990; Cash, 2018). The Appearance Orientation (AO) subscale is a 12-item measure of the extent of one's cognitive-behavioral investment in their appearance. Sample items include, "Before going out, I usually spend a lot of time getting ready," and "I am always trying to improve my physical appearance." Participants respond on a 5-point scale ranging from 1 (definitely disagree) to 5 (definitely agree). Scores are averaged, with higher scores indicating greater appearance orientation. Scores demonstrate internal consistency, construct validity, and good 1-month test-retest reliability in US adult women (Cash, 2018). Cronbach's alpha in the present research was .85 (.80 for women with disabilities, .87 for women without disabilities).

Body Image Disturbance Questionnaire (BIDO; Cash, Phillips, Santos, & *Hrabosky*, 2004). The BIDQ is a 7-item measure of concerns about physical appearance and symptoms of body dysmorphia. Participants rate all items on a 5-point scale ranging from 1 to 5; language for each of the 5 response options differs based on the item. For example, response options for, "Are you concerned about the appearance of some part(s) of your body, which you consider especially unattractive?" range from 1 (not at all concerned) to 5 (extremely concerned), whereas the response options for, "Has your physical "defect" caused you impairment in social, occupational or other important areas of functioning? How much?" range from 1 (no limitation) to 5 (extreme, incapacitating). For the present investigation, the word "defect" was replaced with "difference" to align with person-first language and disability etiquette (Centers for Disease Control and Prevention, n.d.). Scores are averaged; higher scores reflect greater body image disturbance. The BIDQ is internally consistent and shows evidence of construct validity in college-aged women (Cash et al., 2004) and among individuals with idiopathic scoliosis (Auerbach et al., 2014). In the present study, Cronbach's alpha was .90 (.88 for women with disabilities, .90 for women without disabilities).

Situational Inventory of Body Image Dysphoria, short form (SIBID-S; Cash 2002). The SIBID-S is a 20-item measure assessing negative body image affect across a variety of situational contexts (e.g., during exercise, intimacy, eating, social gatherings, etc.). The instrument uses a 5-point scale ranging from 0 (never) to 4 (always or almost always). Scores are averaged, with higher scores reflecting body image dysphoria across a broader range of situational contexts. Researchers have found the SIBID-S internally consistent and stable in US college-aged women, and the short form correlates highly

with the original 48-item measure (r = .95; Cash, 2002). Cronbach's alpha within the current sample was .96 (.95 for women with disabilities, .97 for women without disabilities).

Body Compassion Scale (BCS; Altman, Linfield, Salmon, & Beacham, 2017). The BCS is a 23-item measure of body compassion comprised of three subscales: common humanity, defusion, and acceptance. Sample items from each subscale, respectively, include, "When I feel my body is inadequate in some way, I try to remind myself that feelings of inadequacy are shared by most people," "When I wish some aspect of my body looked different, it feels like no one else understands my struggle," and "I'm tolerant of my body's flaws and inadequacies." Scores are summed for each subscale and for the whole scale; higher scores reflect greater body compassion. The BCS is consistent internally and across samples of college students, and shows evidence of construct validity (Altman et al., 2017). In the present sample, Cronbach's alpha was .92 (.89 for women with disabilities, .93 for women without disabilities) for the whole scale. Internal consistency reliability for each subscale was also acceptable in both groups.

Single Item Self Esteem scale (SISE; Robins, Hendin, & Trzesniewski, 2001).

The SISE asks participants to rate their level of agreement, on a scale of 1 (strongly disagree) to 5 (strongly agree), with the following statement: "I have high self-esteem." As such, higher scores reflect higher self-esteem. The SISE demonstrates validity across various adult populations (Bagley, 2005; Robins et al., 2001) and correlates highly (r = .74 - .80) with the Rosenberg Self-Esteem Scale (Robins et al., 2001; Rosenberg, 1965).

Statistical Analyses

Data were collected in Qualtrics and exported to SPSS Statistical software Version 25 (IBM Corp., Armonk, NY) for analysis. Following removal of cases with more than 40% missing data or failed validity checks as described above, we examined missing data. At this stage, 28.4% of cases were missing at least one data point; however, the percentage of total missing data was low (0.71%). Data were determined to be missing completely at random (MCAR) using Little's test (p = .272). Multiple imputation with fully conditional specification was used to estimate remaining missing values. Based on assessments of skew and kurtosis, data were normally distributed (Kim, 2013).

All 30 items were screened for endorsement and variability rates (i.e., means and standard deviations) prior to entering items into the factor analysis. We then conducted the EFA to assess the factor structure underlying the FABI items and to inform decisions about items to retain for the final scale (Fabrigar & Wegener, 2012; Whitley & Kite, 2013). We used maximum likelihood extraction with direct oblimin rotation to allow factors to correlate. After the factor structure was determined, we removed scale items and computed the total FABI scale score using only retained items.

We assessed item discrimination and internal consistency of the retained items, then computed bivariate correlations to assess the direction and strength of relationships between FABI and selected body image and functionality measures. Due to the multiple comparisons assessed, the p-value was adjusted to .005. We used Fisher's r to ztransformations with an adjusted p-value of .008 to compare correlations between groups.

Lastly, we assessed the incremental validity of the FABI scale using hierarchical regression modeling. Specifically, we modeled the data to explore whether FABI

accounted for additional variance in body image disturbance scores beyond that predicted by functional disability and appearance concerns. We modeled a second hierarchical regression using SIBID-S scores in place of FABI scores to compare models. In both models, we entered the measure of functional disability in Step 1 followed by appearance evaluation and orientation in Step 2. In Model 1, we added FABI in Step 3; in Model 2, we added situational body image dysphoria in Step 3.

Results

Hypothesis 1: Item Analysis and Exploratory Factor Analysis

We conducted initial item analyses on all 30 FABI items. All items correlated with at least one other item (all *r*s between .30 - .70). Means for all items were between 2 and 4 on the 5-point scale, suggesting no issues with ceiling or floor effects (Clark & Watson, 1995). Standard deviations for all items except Items 12, 15, and 16 were greater than 1, suggesting sufficient variability (Whitley & Kite, 2013). Given that these items' standard deviations were close to 1, we retained them for further analysis. Initial extraction showed four factors with eigenvalues above 1.0; three factors were required to account for at least 50% of the variance. These data indicate that at least three, but not more than four factors were required to produce an adequate model.

Evaluation of the scree plot showed a clear "elbow" at three factors, and exploration of model fit determined by root mean square error of approximation (RMSEA) values suggested both the three factor (RMSEA = .054) and four factor solutions (RMSEA = .045) were viable. We therefore conducted two separate EFAs specifying three and four factors. In support of H1, we rejected the three-factor model because it resulted in more significant cross-loadings and grouped items in a conceptually item statistics and factor loadings).

Table 4.2. FABI scale retained items and item statistics

Item	Factor loadings	М	SD	r _{it}
Factor 1: Affective/evaluative				
1. I worry about how I look while I am exercising or doing physical activities.	.786	3.60	1.12	.67
3. I dislike seeing my reflection when I'm doing an activity (e.g., walking by a glass storefront, engaged in an activity in front of a mirror).	.697	3.28	1.15	.61
4. I worry that my body movements look awkward.	.649	3.41	1.15	.61
6. I compare the way my body looks while doing specific activities to how others' bodies look while doing those same things.	.635	3.64	1.02	.67
9. I am self-conscious about the way I look during the physical act of eating or drinking, regardless of the food item or beverage.	.440	3.12	1.23	.63
10. I am concerned about how I look when I am talking and laughing with others.	.446	3.24	1.19	.58
13. I dislike how I look in my clothes when doing activities (e.g., walking, wheeling, exercising, sitting a certain way).	.764	3.39	1.17	.71
14. I worry about how other people evaluate what I look like when they see me moving.	.701	3.31	1.16	.76
19. I am concerned about how my body looks during sex.	.487	3.80	1.17	.56
21. Because of my body's functioning, I feel anxious about participating in social situations.	.664	3.23	1.23	.74
Factor 2: Cognitive-behavioral investment				
12. It is important to me that I appear as physically capable as possible.	.822	3.80	.88	.68
15. Looking strong and functional is important to my overall sense of self.	.820	3.68	.97	.64
16. I make efforts to look as smart or intellectually capable as possible.	.558	3.66	.99	.52
Factor 3: Functional self-presentational				
17. I wear clothing items and/or shoes that are uncomfortable or restrict my movements because doing so helps me look good	.867	2.56	1.24	.58
20. The things I do to enhance my appearance (e.g., how I style my hair, the way I dress) affect the functions and activities I can do.	.544	2.93	1.18	.58
Factor 4: FABIO-O (external) 23. People make assumptions about how my body works based on how I look	.464	3.28	1.14	.57

24. The way people treat me is based on how I look when I'm				
doing specific activities.				
25. My body movements look awkward to others.	.626	2.87	1.13	.67
26. Society's perception of me changes when they see my	.802	2.84	1.03	.75
body in motion.				
27. Other people might think I look good in a photo, but their	.507	3.02	1.14	.63
perception of me would change if they saw me moving about				
in real life.				
28. My relationships with others are influenced by how they	.607	2.73	1.12	.65
see me doing specific activities.				
29. People notice how my body moves when I'm out and	.778	3.09	1.01	.66
about.				

Note. N = 285. FABI-O = FABI-other.

 $r_{\rm it}$ = corrected item total correlation computed using within-factor items only

We initially eliminated 8 items based on their low communality estimates (<.40 = low, .40-.69 = moderate, >.70 = high communalities; Fabrigar, Wegener, MacCallum, & Strahan, 1999) and/or the presence of significant cross-loadings where cross-loading did not theoretically make sense. Generally, we removed items with loadings lower than .40 and items with primary-secondary cross-loading discrepancy less than .20 (Matsunaga, 2010).

Metrics from previous content validity and consensus studies (Dissertation Manuscript 2) such as the Item-Content Validity Index measuring SME agreement about item content validity (Polit & Beck, 2006) and Hedges' *g* values measuring differences in item endorsement among women with and without disabilities also informed retention decisions (see Table 4.3 for indicators that guided item retention decisions). This refinement resulted in a final 22 item scale, with 10 items loading on Factor 1 (i.e., affective/evaluative), 3 items loading on Factor 2 (i.e., cognitive-behavioral investment), 2 items loading on Factor 3 (i.e., functional self-presentational), and 7 items loading on Factor 4 (i.e., FABI-O; see Table 4.2).

	SME Study	Delphi Study		EFA		
Item	Low I- CVI value	High Hedges' g Round 2	Hedges' g increase Round 2	High Friedman's test statistic	Low communality	High cross- loading
1		,	,		,	,
2*		\checkmark	\checkmark		\checkmark	\checkmark
5 4						
5*				\checkmark		\checkmark
6		\checkmark		·		·
7*	\checkmark	·				\checkmark
8*	\checkmark				\checkmark	\checkmark
9				\checkmark		
10					\checkmark	
11*					\checkmark	\checkmark
12						
13	\checkmark		\checkmark			
14				\checkmark		
15			\checkmark			
16	\checkmark		\checkmark			
17		\checkmark		\checkmark		
18*	\checkmark	\checkmark	\checkmark			\checkmark
19			\checkmark			
20	\checkmark			\checkmark		
21	\checkmark	,	,	,	,	
22*	\checkmark	\checkmark	\checkmark	\checkmark	\checkmark	
25 24		/			\checkmark	
24 25		\checkmark				/
25 26						\checkmark
20						
28				\checkmark		
29				\checkmark		
30*				\checkmark		\checkmark

Table 4.3. Metrics considered in item retention decisions

Note. SME = subject matter expert. I-CVI = item content validity index. EFA = exploratory factor analysis.

* = Item deleted from final scale

Hypothesis 2: Retained Item Analysis and Internal Consistency Reliability

Corrected item-total correlations computed using only retained items within each factor suggested that all 22 items had good to excellent discrimination (*r* values ranged from .52 to .76). In support of H2, alpha coefficients were acceptable (i.e., $\alpha < .70$) for three of the four factors and for the whole scale, both within the full sample and for women with and without disabilities (see Table 4.4 for all alpha values). One exception is that the alpha level for the functional self-presentational factor among women without disabilities was just under the cutoff value ($\alpha = .69$); however, it should be noted that this factor was comprised of only two items.

Table 4.4. Internal consistency reliability values by disability group and subscale

Scale	Full sample	Women with disabilities	Women without disabilities
FABI scale	.92	.91	.93
Affective/evaluative subscale	.90	.87	.91
Cognitive-behavioral investment subscale	.78	.84	.70
Functional self-presentational subscale	.73	.77	.69
FABI-O subscale	.88	.88	.87

Hypotheses 3 and 4: Evidence of Construct Validity

Correlations were considered strong for $rs \ge .50$, moderate for rs between .30-.49, weak for rs between .10-.29, and very weak/negligible for rs < .10 (Cohen, 1992). When analyzing women with and without disabilities together, all correlations were in the expected directions, providing evidence of convergent and discriminant validity and largely confirming H3. FABI correlated positively with functional disability (r = .50; p < .001), body image disturbance (r = .63; p < .001), appearance orientation (r = .38; p < .001), and situational body image dysphoria (r = .67; p < .001). FABI was inversely

correlated, as expected, with functionality appreciation (r = -.31; p < .001), appearance evaluation (r = -.43; p < .001), body compassion (r = -.56; p < .001), and self-esteem (r = -.37; p < .001).

In partial confirmation of H4, the directionality of correlations between FABI and other body image and functionality measures was equal across groups (results presented in Table 4.5), although for women with disabilities, relationships between FABI and other variables were typically weaker. For women *without* disabilities, higher FABI scores were significantly *moderately* related to higher functional disability (r = .48, p < .001), lower functionality appreciation, (r = -.41, p < .001), higher appearance orientation (r = .45, p < .001), and lower self-esteem (r = -.49, p < .001), and were significantly *strongly* related to higher situational body image dysphoria (r = .66, p < .001), and lower body compassion (r = -.65, p < .001).

For women *with* disabilities, these relationships were weaker (rs = .40, -.13, .30, -.19, .57, -.25, .64, and -.35, respectively; all ps < .001). Correlations significantly differed for FABI and appearance evaluation (z = -2.68, p = .007), FABI and self-esteem (z = -2.87, p = .004), and FABI and body compassion (z = -3.42, p < .001). Between-group differences for correlations between FABI and functional disability, functionality appreciation, body image disturbance, appearance orientation, and situational body image dysphoria were not statistically significant at the adjusted p-value of .008 (ps = .40, .01, .61, .14,and .77, respectively).

Variable	1	2	3	4	5	6	7	8	9
1. FABI	-	.40	13	.57	25*	.30	.64	35*	19*
2. WHODAS	.48	-	07	.52	10	06	.43	16	04
3. FAS	41	50	-	23	.41	.00	13	.41	.35
4. BIDQ	.61	.48	43	-	41	.18	.62	47	34
5. AE	52*	20	.49	68	-	12	52	.64	.68
6. AO	.45	.02	01	.33	17	-	.28	28	17
7. SIBID-S	.66	.39	35	.66	65	.36	-	58	42
8. BCS	65*	.33	.52	70	.70	39	69	-	.63
9. SISE	49*	20	.48	52	.70	21	61	.62	-
Possible range	1-5	0-48	1-5	1-5	1-5	1-5	0-4	23-115	1-5
$M_{ m with}$ disabilities	3.43	16.47	3.77	2.69	2.75	3.56	2.37	63.80	1.68
$SD_{ m with\ disabilities}$.64	9.93	.71	.93	.89	.62	.90	14.09	1.32
$M_{ m w/o~disabilities}$	3.06	8.69	3.97	2.07	3.01	3.51	1.92	71.30	2.03
$SD_{ m w/o\ disabilities}$.69	9.0	.77	.84	1.02	.72	1.06	16.87	1.36

Table 4.5. Study variable means (M), standard deviations (SD), and correlations by disability status

Note. N = 285 (137 women with disabilities, 148 women without disabilities). Correlations for women with disabilities are above the diagonal, and correlations for women without disabilities are below the diagonal.

* = Fisher's transformation comparison of z scores significantly different at p < .008 for FABI comparisons

Hypotheses 5 and 6: Incremental Validity

As expected in H5, hierarchical regression modeling showed that FABI scale scores accounted for an additional 3.5% of variance in body image disturbance scores beyond that explained by the selected measures of function and appearance (WHODAS, AE, and AO; results presented in Table 4.6). Also supporting H6, the second hierarchical model suggested that although situational body image dysphoria also accounted for additional variance beyond these measures, it accounted for slightly *less* variance in body image disturbance scores (2.7%) beyond the same measures of function and appearance than did FABI.

	Adj. R ²	ΔR^2	ΔF	β	t
Model 1	•				
Step 1	.322	.322	134.67**		
WHODAS				.052	11.61**
Step 2	.569	.246	80.26**		
WHODAS				.045	12.10**
AE				413	-10.78**
AO				.269	5.08**
Step 3	.604	.035	24.73**		
WHODAS				.034	8.31**
AE				350	-8.99**
AO				.133	2.31*
FABI				.351	4.97**
Model 2					
Step 3	.590	.027	12.06**		
WHODAS				.036	9.00**
AE				294	-6.39**
AO				.189	3.49*
SIBID-S				.226	4.37**

Table 4.6. Hierarchical regression models to test incremental validity

Note. * = significant at p < .05, ** = significant at p < .001

Steps 1 and 2 in Model 2 are not shown because they are the same as Steps 1 and 2 in Model 1

Discussion

This study aimed to assess the factor structure and validity of the functional-

aesthetic body image scale. We conducted EFA, assessed correlations between FABI and

selected measures of body image and body functionality, and modeled hierarchical

regressions to explore the scale's psychometric properties.

Hypothesis 1: Exploratory Factor Analysis

Partially confirming our hypothesis, EFA revealed four factors:

affective/evaluative (i.e., a person's functional-aesthetic appraisals and related emotions);

cognitive-behavioral investment (i.e., a person's cognitive and behavioral investment in

their functional-aesthetic); functional self-presentational (i.e., a person's specific

impression management techniques related to functional-aesthetic body image); and

FABI-O (i.e., a person's perceptions of how others appraise or evaluate their body while it is engaged in functions). Although we hypothesized that the EFA would reveal a fourfactor model, the four factors emerged with a slightly different pattern than expected.

The retained items that loaded on the FABI-O factor loaded as designed and hypothesized. Retained items intended to measure the affective/evaluative domain loaded almost exactly as designed. One discrepancy was that we initially designed Item 6 ("I compare the way *my* body looks while doing specific activities to how *others*' bodies look while doing those same things") to address behavioral investment, however the item clearly reflects a cognitive-*evaluative* perspective. It therefore makes sense theoretically that this item loaded on the affective/evaluative domain.

We originally designed six items intended to measure a cognitive domain and three items intended to measure a behavioral domain; however, the retained items from these categories loaded on the same factor. As a result, the cognitive and behavioral investment domains were integrated into a cognitive-behavioral investment domain. We accepted this model given that previously published scales in the body image literature have also suggested an integrated cognitive-behavioral investment domain (e.g., Cash, 1994b, 2000).

Interestingly, two items we developed to cover the behavioral domain loaded on a distinct factor. These two items reflect aspects of self-presentation or "impression management" (Bailey, Gammage, van Ingen, & Ditor, 2016; Leary & Kowalski, 1990; Read, Hill, Jowett, & Astill, 2019) that, contrary to our hypothesis, clearly differed from the cognitive-behavioral investment domain. We refer to this factor as "functional self-presentational," as it goes beyond appearance strategies to include functional concerns.

These two items (Item 17: "I wear clothing items and/or shoes that are uncomfortable or restrict my movements because doing so helps me fit in" and Item 20: "The things I do to enhance my appearance [e.g., how I style my hair, the way I dress] affect the functions and activities I can do") focus on specific functional-aesthetic management strategies (e.g., grooming and dressing), while the three items that currently comprise the cognitive-behavioral investment domain address more general strategies (e.g., "looking smart") and the importance of or value placed on functional-aesthetics, potentially explaining the loading pattern.

Given that only three items loaded on the cognitive-behavioral investment factor and two items loaded on the functional self-presentational factor, we will need to develop additional items from the initial qualitative data to address these factors prior to the next phase in scale validation. Doing so will increase the utility of the scale and its subscales for researchers who wish to use the subscales as standalone measurement instruments.

Hypothesis 2: Item Analysis and Internal Consistency Reliability

Findings largely confirmed Hypothesis 2. The internal consistency of all scale items together and for each potential subscale was acceptable in the full sample and separately for women with and without disabilities, with one exception. The alpha level for the functional self-presentational factor among women without disabilities was just under the cutoff value ($\alpha = .69$); however, this finding was not considered problematic because only two items loaded on this factor. We expect that after developing additional items to address this domain, the alpha level among this group will improve.

Hypotheses 3 and 4: Construct Validity

The FABI scale demonstrates good convergent and discriminant validity. All correlations between FABI and other measures representing the nomological network were in the hypothesized directions for the full sample and between groups, partially confirming H3 and H4. However, correlations between FABI and select body image measures (appearance evaluation, self-esteem, and body compassion) were significantly weaker among women with disabilities. One explanation for this difference is that to our knowledge, the instruments selected to measure these variables had not previously been validated among women with disabilities, and therefore may not function the same across the study populations. This finding points to the importance of including people with disabilities in all scale development and testing studies, as this population comprises nearly a quarter of the US adult population and about 15% of the population globally (Dissertation Manuscript 2; Okoro et al., 2018; World Health Organization, 2011).

Another potential explanation for the difference in correlations between study populations is that the relationships between these variables may differ between these groups. This finding would suggest differences in the ways that women with and without disabilities conceptualize and experience these aspects of self-esteem and body image. For example, it is logical to hypothesize that women with disabilities may be more equipped to cultivate body compassion despite having body image concerns. Research has shown that individuals with spinal cord injury experience body acceptance as a core domain of positive body image (Bailey, Gammage, van Ingen, & Ditor, 2015) and that individuals with physical disabilities experience gradual adjustment to and acceptance of their different bodies and disabilities over time (Taleporos & McCabe, 2002). Scholars explain that disability/body acceptance may be *necessary* to foster positive adjustment to spinal cord injury (Wright, 1983), partially explaining the weaker relationships between body image concerns (or low FABI) and positive body image constructs among those with acquired disabilities. More research exploring body image by disability status, and particularly among those with acquired vs. congenital disabilities, is needed.

The correlations between FABI and functionality appreciation are particularly insightful. The constructs were weakly and inversely correlated in the overall sample, and even more weakly linked among women with disabilities. These findings provide preliminary evidence that positive and negative aspects of body functionality, much like positive and negative overall body image (Tylka & Wood-Barcalow, 2015), exist on distinct continua and may be experienced simultaneously. That is, a person's concerns about their function/functional-aesthetic body image do not preclude them from also expressing gratitude for and appreciating what their bodies do for them (Alleva et al., 2018). These findings provide additional support for expanding the definition of body functionality and reevaluating its theoretical relationships (Vinoski Thomas et al., 2019).

Hypotheses 5 and 6: Incremental Validity

Lastly, our findings demonstrate that FABI is a unique construct in that it accounts for a small, yet significant amount of additional variance (3.5%) in body image disturbance scores beyond that explained by measures of function and appearance evaluation and orientation separately. Findings also suggest FABI accounted for *more* additional variance in body image disturbance that the SIBID-S measure (which accounted for 2.7% additional variance). This finding was important, as several FABI items overlap with those found on the SIBID-S, although the rationale for inclusion of these items in the scales differs. Our findings suggest that FABI is more than just another measure of state-specific body image, and results provide additional evidence that it is a unique construct.

Study Limitations and Strengths

The present study is subject to limitations that may reduce its generalizability. First, we recruited only women to participate in this phase of the research, as we developed and refined the scale based on qualitative interviews conducted solely with women. Body functionality is an important component of male body image (Mulgrew, Johnson, Lane, & Katsikitis, 2014; Franzoi, 1995), and future research should also explore FABI and related constructs among men. It may also be interesting to explore FABI among those who are gender nonconforming. Relatedly, the sample recruited for the present study was predominately White and relatively young, with a mean age in the low 30s. Future research should also explore the FABI construct and scale in racially/ethnically diverse samples and among older adults. We suggest that researchers investigate the FABI construct qualitatively in these diverse populations prior to exploring measurement, for example, by conducting cognitive interviews (Willis, 2005).

We selected a network of measures of appearance and function to use in the validation study that were accessible and kept the online survey to a reasonable length given our limited resources. There are several other measures that would have been valuable to include in the study, such as measures of perfectionistic self-presentation (e.g., the Perfectionistic Self-Presentation Scale [PSPS]; Hewitt et al., 2003), body acceptance by others (e.g., Body Acceptance By Others scale [BABO]; Avalos & Tylka, 2006), and body shame, guilt, and pride (e.g., the Body and Appearance Self-Conscious
Emotions Scale [BASES]; Castonguay, Sabiston, Crocker, & Mack, 2014). The PSPS would be particularly valuable given the functional self-presentational factor that emerged in the EFA process. Lastly, it may be important to consider using a measure of disability *identity* (e.g., the Disability Identity Development Scale [DIDS]; Forber-Pratt, 2018; Forber-Pratt & Zape, 2017) in addition to measures of functional disability to understand how identification with disability as a facet of identity or culture might influence relationships with body image variables. We will consider including these measures in future research exploring the properties of the FABI scale.

Study limitations are balanced by several strengths. Ours is the first known scale validation study in the field of body image to intentionally recruit a national, mixedability sample and specifically analyze differences between disability groups. We included a wide range of disabilities, including mobility disabilities, intellectual and developmental disabilities, chronic medical conditions, and mental health disabilities among others, and the self-reported data was quite consistent with the validated measure of disability. This approach provided insightful information about body image among women with disabilities. We implemented a rigorous Universal Design for Measurement approach by deriving scale items from qualitative interviews of women with visible physical disabilities; collecting disability demographic data using both self-report and a validated measure of functional disability; and using qualitative and quantitative data about scale items from SMEs and community women with and without disabilities to guide item retention decisions (Dissertation Manuscript 2). The present study also implemented a rigorous method for exploring the incremental validity of the scale, which demonstrates the unique contribution of the FABI construct and scale to the field.

Implications

Overall, our findings suggest that it is feasible, acceptable, and *necessary* to include people with disabilities in studies of body image measurement. Researchers should consider collecting demographic data about disability when conducting all scale development, validation, and other types of measurement studies. For research that involves a functionality component, it may be helpful to use a self-report measure as well as a validated measure of disability such as the WHODAS (Üstün & WHO, 2010). The US Department of Health and Human Services (HHS) has recently included six standardized disability questions in all federal health surveys (Centers for Disease Control and Prevention, 2019; HHS, 2011). Using these standardized self-report items in measurement research will allow for researchers to understand the prevalence of various types of disabilities within their samples and to make comparisons between studies.

The FABI scale may be useful in variety of research contexts. For example, researchers should consider using the FABI scale in studies testing the effects of exposure to idealized and non-idealized athletic or "body-as-process" videos and images on body image outcomes (e.g., Mask, Blanchard, & Baker, 2014; Mulgrew & Hennes, 2015; Mulgrew, McCulloch, Farren, Prichard, & Lim, 2018; Mulgrew & Tiggemann, 2018). FABI would also be useful to measure in other studies testing whether focusing on one's personal body functionality via writing tasks improve body image (e.g., Alleva et al., 2014, 2015; Mulgrew, Stalley, & Tiggemann, 2017; Stern & Engeln, 2018). These studies have previously found that although functionality-focused campaigns and activities may yield positive body image outcomes among women, the maintenance of these outcomes after viewing idealized functionality- or appearance-focused images is somewhat limited (Alleva et al., 2016; Mulgrew et al., 2018), supporting the importance of the intersection between appearance and functionality (i.e., FABI) to women's overall body image.

The FABI scale may also have additional utility as a tool for clinicians. For example, the FABI scale may be useful, perhaps in combination with the Functionality Appreciation Scale (Alleva et al., 2017) among clinicians working with people with recent spinal cord or other traumatic injury. Body image concerns are known to affect the rehabilitation process for people with disabilities related to these conditions (Bailey et al., 2016; Sheldon, Renwick, & Yoshida, 2011; van Diemen, van Leeuwen, van Nes, Geertzen, & Post, 2017); it is logical to hypothesize that functional-aesthetic concerns may be particularly salient. Lastly, the scale may have utility in clinical programs and/or intervention research promoting health behaviors such as physical activity and balanced eating among people with disabilities identified the functional-aesthetic aspects of exercising and eating as salient for in the initial qualitative study from which we derived items (Vinoski Thomas et al., 2019).

Conclusions and Future Directions

The 22-item FABI scale in its current format is a valid measure of functionalaesthetic body image among a broad population including women with and without disabilities. However, additional development and research is needed to maximize the scale's utility and further assess its dimensionality. An immediate next step is to develop additional scale items for the cognitive-behavioral investment (currently comprised of three items) and functional self-presentational (currently comprised of two items) domains so that researchers can eventually use these subscales as standalone instruments to measure only these domains. We will derive these additional items from qualitative studies exploring body image and body functionality among individuals with disabilities (e.g., Bailey et al., 2015; Vinoski Thomas et al., 2019) and within the general population.

Next we suggest that the scale undergo further testing. For example, exploring the scale's reliability (e.g., test-retest) and its correlations with additional measures, such as the Perfectionistic Self-Presentation Scale (Hewitt et al., 2003) and the Body Acceptance By Others measure (Avalos & Tylka, 2006) to provide additional evidence of its construct validity. A confirmatory factor analysis should be conducted on data collected from a separate but similar mixed-ability sample (to avoid sample bias; Fokkema & Greiff, 2017; Swami & Barron, 2018) to confirm the factor structure found in the present analysis (Worthington & Whittaker, 2006). The scale's measurement equivalence between women with and without disabilities should be explored through measurement invariance analysis, and, if necessary, analyses of differential item functioning (Swami & Barron, 2018). The FABI scale is a valuable addition to the set of extant measures focusing on body functionality and demonstrates advances in the inclusion of diverse populations within measurement research.

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CHAPTER 5: DISCUSSION

Body image is an important contributor to women's health. Research has explored, with mixed findings, whether focusing on body functionality rather than appearance may enhance women's positive body image and help buffer negative body image factors linked to poor health behaviors and outcomes (Abbott & Barber, 2010; Alleva et al., 2014, 2015, 2016, 2017; Mask, Blanchard, & Baker, 2014; Mulgrew & Hennes, 2015; Mulgrew, McCulloch, Farren, Prichard, & Lim, 2018; Mulgrew & Tiggemann, 2018; Mulgrew, Stalley, & Tiggemann, 2017; Stern & Engeln, 2018). Despite this expanding literature, the concept of body functionality and its relationships with appearance-related factors is underexplored among women who have differences in their body functionality (Alleva et al., 2018; Bailey, Gammage, van Ingen, & Ditor, 2015). These relationships warrant further exploration given the disproportionately poor health status of women with disabilities, and the unique differences in body image they may experience due to differences in appearance and functionality (Gorgey & Dudley, 2007; Krahn, Klein-Walker, & Correa-de-Araujo, 2015).

The present research addressed this gap by clarifying and measuring relevant aspects of body functionality among women with *and without* disabilities. The multiphase study began with a qualitative exploration of body functionality and appearance themes solely among women with visible physical disabilities and progressed toward the development and validation of a measure of functional-aesthetic body image (FABI) validated within a broad population of women with a range of disabilities (e.g., mobility disabilities, intellectual disabilities, chronic medical conditions, etc.) and women without disabilities. The three phases of research and resulting manuscripts collectively present a cohesive work supporting the extension of body conceptualization theory (Franzoi, 1995) to include FABI and the development of a framework for including people with disabilities within mainstream measurement research.

Review of Findings

The Phase I research was a constructivist grounded theory study exploring body image, with a focus on body functionality and appearance themes, among 15 women with visible physical disabilities (Vinoski Thomas et al., 2019). This study specifically aimed to (a) understand how women with a range of acquired and congenital disabilities define and experience body image and body functionality, and (b) explore how body functionality contributes to overall body image among this population.

Four main themes emerged. First, participants described their meanings and definitions of body image and body functionality in ways that both confirmed previous research and offered novel perspectives, particularly concerning the concept of body functionality. For example, participants believed that the term "body functionality" should encompass what the body can *and cannot* do, given that the discord between societal expectations about what the body can do and what participants' bodies can and *cannot do* substantially influenced participants' body image and self-concept. Second, participants discussed experiencing fluctuations in their body image that aligned with changes in their physical symptomatology and mental health. This finding illuminated unique issues in the understanding and measurement of body image concepts among populations that experience disabilities and other health issues that may affect body image stability.

Phase I participants discussed many factors related to body functionality and appearance that positively and negatively influenced their overall body image. Factors related to body functionality, such as bladder and bowel functionality and the process by which women with visible physical disabilities make functionality comparisons with others, were more often described as negatively influencing body image. Appearancerelated factors centered on facial features and hair, and were typically described in a positive manner.

A unique and ultimately foundational theme emerging from the Phase I research was the interaction of appearance and body functionality. The extant literature describes body functionality and appearance as two distinct components of body image and often considers them antithetical (Franzoi, 1995; Frederickson & Roberts, 1997; McKinley & Hyde, 1996). However, women with visible physical disabilities who participated in the present research described instances in which appearance and functionality concerns overlapped (e.g., "what I look like while I'm engaged in specific functions") as the most salient factors contributing to their overall body image. The development of this concept, termed "functional-aesthetic body image" became the focus of the subsequent research phases.

Phase II was comprised of the development, content validation, and consensus testing of items to be included on the functional-aesthetic body image (FABI) scale. I derived items by reviewing the Phase I qualitative data coded as representing FABI and transforming relevant quotes into scale items. Extant literature also supported several items (Asai, Kanayama, Imaizumi, Kyama, & Kaganoi, 2016; Breakey, 1997; Suendermann, Rydberg, Linder, & Linton, 2018). In Phase IIa, subject matter experts

(SMEs; N = 6) reviewed the item pool, instructions, and response options to establish face validity. SMEs provided quantitative ratings of content validity and commented qualitatively on each item. The majority of items received adequate content validity ratings; those that did not were modified and retained for the next study. In Phase IIb, 33 community women with (n = 18) and without (n = 15) disabilities participated in an online Delphi panel to evaluate the relevance and acceptability of the items. Delphi panel participants provided initial quantitative ratings and qualitative feedback about item relevance in Round 1. Comments were compiled and provided to participants; they rated items again in Round 2. The magnitude of group differences (i.e., women with disabilities compared with women without disabilities) was computed for each round. Findings suggested most items were relevant for both groups. Furthermore, the magnitude of difference in ratings decreased between rounds for the majority of items, providing evidence that the Delphi process was successful in moving toward consensus about item relevance. The process ultimately prompted the development of guidelines for a Universal Design for Measurement (UDM) framework.

In Phase III, I explored the factor structure and psychometric properties of the FABI scale in a sample of 285 women with (n = 137) and without (n = 148) disabilities recruited from Amazon's MTurk. The exploratory factor analysis revealed a four-factor structure, with items loading on an affective/evaluative factor, a cognitive-behavioral investment factor, a functional self-presentational factor, and a self-perceived perceptions of others factor (FABI-O). Items with high and illogical cross-loadings and low communalities were removed, resulting in a 22-item scale. The 22-item scale correlated positively with a measure of functional disability and other measures of negative body

image, and correlated inversely with self-esteem and measures of positive body image, as expected, providing initial evidence of convergent and discriminant validity. FABI scale scores accounted for unique variance in overall body image disturbance above and beyond that predicted separately by measures of function and appearance, providing evidence for the scale's incremental validity. The FABI scale also accounted for more variance in body image disturbance scores than did a measure of state-specific body image, providing evidence that FABI is a unique construct beyond a state measure.

Collective Implications

Each of the three studies have implications for theory, measurement, and public health research and practice. The Phase I study is the first known research to lead to the development of a comprehensive definition, including the concepts and boundaries, of the construct of body functionality using qualitative methodology (Vinoski Thomas et al., 2019). This study is also among the first to examine body functionality that included women with a range of visible physical disabilities or limitations in function (Alleva et al., 2018). The Phase I study findings contribute to and build upon existing theory describing how body functionality influences overall body image and how this construct may manifest differently among women with visible physical disabilities. The study therefore serves as an application of feminist disability theory (Garland-Thomson, 2002), by demonstrating how recognizing disability as an additional identity that influences women's experiences can illuminate nuances and previously unexplored relationships in extant feminist theory (Garland-Thomson, 2002). The study findings have the potential to inform clinical practice and interventions promoting positive body image among a broader range of individuals.

The Phase II study has several implications for research and measurement in the fields of body image and public health. Swami and Barron (2018) recently published a comprehensive guide to adapting body image scales for use in broader populations, reinforcing that the inclusion of broader populations within the field of body image necessitates better measurement solutions. This guide is useful for adapting *existing* measures; however, researchers may benefit from additional guidance on the development of *new* measures. In Phase II, the basic principles of Universal Design guided the development of a FABI measure that is not *specific* to the experiences of women with disabilities but rather considers factors experienced by women with disabilities within the range of body image-related factors experienced by all women. This research resulted in the development of the UDM framework, a promising approach to enhance the inclusion of people with disabilities in mainstream health research. The framework has the potential to further guide the universal design of measurement instruments so that they are relevant for other marginalized groups– and, importantly, individuals who embrace multiple marginalized identities.

The Phase III research resulted in a FABI scale validated for use among women with and without disabilities. The scale will be useful for body image researchers interested in testing how a body functionality focus affects body image outcomes among women and within more diverse groups. The scale will also be useful for clinicians; for example, it may be a useful tool for those working with people with acquired disabilities (e.g., spinal cord injury) as part of the rehabilitation process. The study has various implications for measurement research; for example, the correlations computed in the

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study to explore criterion-related validity demonstrate the importance of collecting disability demographic data when conducting scale development and related studies.

The studies collectively address a critical gap in the inclusion of persons with disabilities within mainstream health and body image research. The research demonstrates possibilities for and the importance of not only *including* people with disabilities within body image research, but *centering* their experiences and insight in the conceptualization and measurement of new constructs.

Centering is a concept that has seen recent growth in the field of health disparities research (Thomas, Quinn, Butler, Fryer, & Garza, 2011). The concept stems from Critical Race Theory and refers to the tenet of "centering in the margins," or the act of redistributing the focus or starting point of a given issue from the majority or dominant group's perspective to that of the marginalized group (Delgado & Stefancic, 2001; Ford & Airhihenbuwa, 2010). Principles of Critical Race Theory have been adopted and conceptualized into a Critical Disability Theory, which posits, among other arguments and in line with feminist disability theory, that people with disabilities have unique and complex experiences and insights into the human condition (Garland-Thomson, 2002; Gleeson, 1999; Rocco, 2005) that can and should guide the development of research and policies that affect their well-being. Centering therefore goes beyond inclusion by not only welcoming but *prioritizing* these unique insights.

Although public health scholars are increasingly using this terminology, literature that demonstrates what centering marginalized populations might look like in terms of research methodology are critically underexplored (Pàlencia, Malmusi, & Borrell, 2014). Most notably, the three phases of this research together provide an example of methodological centering, by shifting the development of measurement instruments from a preliminary focus on the dominant group and subsequent adaptation for marginalized groups (Swami & Barron, 2018), to developing the instrument based on the unique perspectives of the marginalized group, explored via qualitative inquiry, and then assessing the relevance and applicability of the content within a broader population. I encourage public health researchers and others in fields concerned with promoting health equity to further consider how the insights and lived experiences of marginalized groups, and particularly those with multiple and intersecting marginalized identities, can be included and spotlighted within research designs.

Overall Limitations

Although the three manuscripts comprising this dissertation present limitations of each specific study, overall limitations warrant further discussion. As a whole, the study samples showed broad disability diversity, including people with acquired and congenital physical disabilities, and, in later phases, people with varying disability types such as cognitive disabilities and chronic medical conditions. However, across all three studies, samples were limited in their gender, age, educational, and racial/ethnic diversity, limiting the transferability and generalizability of the findings.

I designed the overall research to focus on body functionality and body image solely among women, so this aspect of limited gender representation should be considered a *delimitation*, as the samples were limited by design. However, in each study, I specifically invited women who "identified as women in a way that was meaningful to them" as a way to be inclusive of the various ways in which individuals express their gender identity. Thus, the samples may have included women who identify as transgender, but I did not expressly ask participants whether they identified this way. Body image among transgender populations is a *critically* important area of research (McGuire, Doty, Catalpa, & Ola, 2016), and FABI may be a particularly interesting concept to specifically explore within this population in future research.

The age of participants in Phase I was limited to those between 18 and 55 years old by design, resulting in a mean age of approximately 33 years. Study Phases II and III, however, did not have an upper age limit, yet participants' mean ages were still in the 30s. All studies also included participants with relatively high educational attainment, and limited racial/ethnic diversity. The use of web-based recruitment methods, a webbased eligibility survey, and interviews over video-conferencing or phone may have resulted in this younger mean age, increased educational attainment, and reduced racial/ethnic diversity of participants in the three studies. Particularly among those with disabilities, those who are older, have lower education, or who are not White may be among the most marginalized, and may lack access to the technology required to participate in the studies. Researchers wishing to include these more diverse groups within their samples should consider diversifying their recruitment strategies (e.g., using word-of-mouth in addition to web-based techniques, using target recruitment, etc.) to achieve this goal.

A related limitation was that each study included in this research used nonprobability sampling methods. Non-probability sampling should not be considered a limitation in the qualitative research or expert content validation studies, as these designs necessitate non-probability samples. However, the Delphi panel and scale validation studies used convenience and self-selected samples, limiting the generalizability of the findings (Morgado, Meireles, Neves, Amaral, & Ferriera, 2017).

Study Strengths

Despite its limitations, this research presents a highly rigorous mixed-method investigation strengthened by its triangulation of multiple guiding theories and inclusion of multiple perspectives (e.g., insight from field experts as well as people with lived experience) in all three studies.

The rigor of the various approaches used in this dissertation has been described throughout. The Phase I study presents rigorous methodological and interpretive approaches as defined by established guidelines for rigor in grounded theory studies (Lincoln & Guba, 1985; Chiovitti & Piran, 2003). For example, I conducted member checks and worked with a second coder to enhance the study's credibility, and kept field notes and reflexive journals to enhance the study's dependability (Ortlipp, 2008).

I also conducted the scale development studies in line with published recommendations for increasing rigor in measurement research (Morgado et al., 2017). Most importantly, the measurement studies used both inductive and deductive approaches (e.g., qualitative interviews and searching extant literature) to develop items and conceptualize and operationalize the construct (DeVellis, 2003; Morgado et al., 2017). The rigor of the theoretical analysis (i.e., content validity) phase of the measurement research was enhanced by the incorporation of perspectives from both SMEs and laypersons with and without disabilities. Most measurement studies use only SMEs in the theoretical analysis of items, and many do not clearly report the methods by which they assess content validity (Morgado et al., 2017); the present study is strong in this regard. Another strength of the dissertation was its triangulation of multiple guiding theoretical perspectives (Denzin, 1978). The research drew upon concepts from several body image theories, including objectification theory (Fredrickson & Roberts, 1997), body conceptualization theory (Franzoi, 1995), and theories of embodiment (Menzel & Levine, 2011; Piran & Teall, 2012); and prominent disability frameworks such as the social model of disability (Finkelstein, 1980; Oliver, 1990), universal design (Center for Universal Design, 1997; Williams & Moore, 2011), feminist disability theory (Garland-Thomson, 2002), and critical race and disability theories (Delgado & Stefancic, 2001; Ford & Airhihenbuwa, 2010; Rocco, 2005) in its design and interpretation.

Lastly, the research was strengthened by its triangulation of evidence (Brownson, Fielding, & Maylahn, 2009; Steckler, McLeroy, Goodman, Bird, & McCormick, 1992; Tones, 1997) through the recruitment of multiple samples and use of complementary analytical methods. Across all three studies, participants (e.g., SMEs, women with visible physical disabilities in the qualitative study, and women with varying disabilities and women without disabilities who participated in the Delphi and scale validation studies) represented diverging backgrounds and experiences with issues of body image and disability. None of the women with or without disabilities recruited in this research participated in more than one study phase. The overall research used multiple qualitative and quantitative methods to elicit information from these samples, providing preliminary evidence of the study's external validity.

Retrospective Reflexivity

As a feminist social constructionist, I recognize the importance of documenting my perspectives to provide transparency about how my identities, training, and experiences may have influenced the research (Findlay, 2002). To this end, I engaged in reflexivity throughout the dissertation process. My identity and training as a researcher influenced the overall dissertation design, implementation, analysis, and interpretation. "Nothing about us without us" is a common phrase shared in the disability rights movement (Charlton, 1998) and refers to the idea that people with disabilities have the fundamental right to be centered in all processes that involve their well-being. Research is no exception. The overall constructivist framework applied throughout this dissertation was foundational to the inclusion of and co-creation of knowledge with people with disabilities in all stages of the research.

In my experiences working with individuals with disabilities, I have received formal and informal training on "disability etiquette." Although I consider this experience a strength of the study in terms of my ability to build trust within the community, I have also reflected upon ways that this training may have inhibited the research. For example, during the qualitative research process, I felt this etiquette may have prevented me from asking certain specific questions about participants' conditions (e.g., inquiring about how an injury happened) because I did not want to offend participants nor risk losing their trust. It is possible that someone who received less of this training or had less familiarity with topics that are considered less acceptable to discuss may have uncovered more detailed information about participants' conditions and experiences.

I have ingrained privileges, as a young and currently non-disabled woman, which may have further influenced the research process. Women in the qualitative study may not have disclosed specific topics with me, or may have used different language with me, because I have not personally experienced disability. My position as an academic from a middle-class background may have also influenced interviews. I reflected throughout the qualitative study whether asking people about their body image on a "typical day," was ableist or classist in itself. People who are unemployed or engaged in shift or freelance work, or people who have disabilities and health conditions that fluctuate day-to-day, may not have what we in more privileged positions might consider a "typical day" or routine. Participants in my study were highly educated, so this issue hay have been less relevant, but the revelation informed my thinking about future research.

I reflected upon similar sentiments in the development and testing of the FABI scale items. I derived items from qualitative interviews with women with visible physical disabilities. In line with constructivist traditions, and to enhance the rigor of the scale development research, it was important to me that I retained participants' words and phrasing within the scale items as often as possible. When SMEs reviewed the items, they often offered alternative phrasing that they felt made more sense theoretically or empirically, or aligned better with their reading of the construct conceptualization. In this process, I felt at odds between upholding the original participants' contributions and valuing experts' opinions. As a result, I opted to revise some items, but ultimately retain all 30 initial items until the end of Phase III, to ensure I had a variety of metrics from a range of individuals (including SMEs and multiple samples of women with and without disabilities) to guide item retention decisions. It was during this process that I realized that scale development is as much an art as it is a science. Designing an instrument that is psychometrically sound and relevant to the communities in which it will be used necessitates striking a delicate balance, between the input of those with lived experience and those with subject matter expertise, for which there is no prescription. Throughout

the dissertation process, I had opportunities to disseminate the qualitative portion of the research to the disability community (Vinoski Thomas, 2018) and to the research community (Vinoski Thomas et al., 2019). The work has been well received by both groups, demonstrating that I was somewhat successful in striking this balance.

Future Directions

This dissertation has yielded multiple avenues for future body image and disability research. The Phase III research suggested that the FABI scale is a psychometrically sound measure; however, additional research is needed to confirm the scale's factor structure and explore additional evidence of construct validity. Therefore, the most immediate future research will focus on the development of additional items for the cognitive/behavioral and functional self-presentational subscales, which had three items and two items each, respectively, and re-testing the factor structure through confirmatory factor analysis. After I complete this research, I will consider the FABI scale finalized and ready for use within other studies.

Other avenues for future research emerged from the earlier phases. For example, a Phase I study participant who experienced spinal cord injury mentioned that discussing body functionality as a component of body image with her rehabilitation counselors may have been helpful in her rehabilitation process. Scholars have explored body image challenges among people with spinal cord injury; most of these studies mention changes in function and appearance and resulting body image concerns as highly relevant to mental health and physical rehabilitation (Bailey, Gammage, van Ingen, & Ditor, 2016; Bassett & Martin Ginis, 2009; Burns, Hough, Boyd, & Hill, 2010; Chau et al., 2008; DeSanto-Madeya, 2006; Hamblin, 2013; Pazzaglia, Galli, Scivoletto, & Molinari, 2013; Potgieter & Khan, 2005; Sheldon, Renwick, & Yoshida, 2011; van Diemen, van Leeuwen, van Nes, Geertzen, & Post, 2017). Future research should explore how rehabilitation counselors and other health professionals working with people with spinal cord injury are trained to address body image and body functionality, and use this information to develop training materials for rehabilitation professionals to discuss functional-aesthetic body image with patients.

It would also be valuable to extend the Phase II research exploring the UDM framework by applying the framework to measurement studies that seek to include other marginalized groups, such as sexual minority populations. Although the principles of universal design are rooted in the social model of disability (Center for Universal Design, 1997), the guidelines comprising the UDM framework have the potential to apply to other marginalized groups. This is a critical step toward centering the *multiple* oppressed identities of those who experience the most substantial health disparities.

The overall research sparks inquiry into the proportion of studies in and beyond the field of body image that collect disability demographic data and/or use exclusion criteria that result in the unnecessary exclusion of people with disabilities from mainstream research. It would be interesting to explore the prevalence of studies within specific fields (e.g., public health) that collect and report demographic disability data within studies. It would also be interesting to interview researchers to understand barriers to collecting this data (e.g., ignorance of disability as an important demographic variable, ethical concerns, lack of training about how to make study materials accessible, etc.). This last point underscores the importance of increasing training for students in public health and related disciplines about disability as a facet of identity and about people with disabilities as a marginalized population that experiences health inequities (Sinclair, Tanenhaus, Courtney-Long, & Eaton, 2015; Tanenhaus, Meyers, & Harbison, 2000). **Conclusion**

Women with visible physical disabilities possess distinctive perspectives about body image, particularly regarding the intricate relationship between body functionality and appearance. Most notably, these women report experiencing aspects of functionality and appearance in an integrated manner. Through this research, these women's perspectives stimulated the emergence of a new body image construct, functionalaesthetic body image, challenging previous assertions that body functionality and appearance concepts exist in opposition to one another. Although the emerging concept resulted from qualitative interviews of women with visible physical disabilities, the development and testing of a functional-aesthetic body image measurement scale showed that the concept and its domains are endorsed by women representing a broad spectrum of abilities, including those with varying disability types and those without disabilities.

The novel insights transpiring from this research may transform the study of positive body image and advance the inclusion and methodological centering of people with disabilities and other marginalized groups within the fields of body image, psychometrics, and public health. Researchers and practitioners are encouraged to utilize and expand upon the concepts and frameworks developed through this research to reveal more nuanced understandings of the ways people with disabilities navigate the world in their bodies, and to promote improved holistic health outcomes for all.

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APPENDIX A: ETHICAL APPROVAL LETTERS



OFFICE OF RESEARCH COMPLIANCE 9201 University City Boulevard 319 Cameron Hall Charlotte NC 28223-0001 (704)-687-1871 Web site: http://research.uncc.edu/ Federalwide Assurance (FWA) #00000649

To: Erin Thomas Public Health Sciences

From: Office of Research Compliance

Date: 3/28/2018 RE: Notice of Approval of Exemption with No End Date Exemption Category: 2. Survey, interview, public observation Study #: 18-0125

Study Title: Qualitative exploration and measurement of body functionality among women with physical disabilities

This submission has been reviewed by the Office of Research Compliance and was determined to meet the Exempt category cited above under 45 CFR 46.101(b). This determination has no expiration or end date and is not subject to an annual continuing review. However, you are required to obtain IRB approval for all changes to any aspect of this study before they can be implemented.

The Investigator Responsibilities listed below applies to this study only. Carefully review the Investigator Responsibilities.

Study Description:

Little is known about body image among women with physical disabilities. Researchers are studying how body functionality, or everything the body can do, affects overall body image; however, no studies have explored how body functionality relates to body image among women with physical disabilities. The proposed study will qualitatively explore themes about body functionality and body image among this population. Up to 20 women will be recruited to participate in qualitative interviews conducted via video interfacing technology. Interviews will include semi-structured questions as well as a cognitive interviewing component using an existing measurement scale of body functionality appreciation. Results will be used to inform theory and the development of a new measurement scale.

Your approved consent forms (if applicable) and other documents are available online at http://uncc.myresearchonline.org/irb/index.cfm?event=home.dashboard.irbStudyManagement&irb_id=18-0125.

Investigator's Responsibilities:

The above-cited determination has no expiration or end date and is not subject to annual continuing review.

However, the Principal Investigator needs to comply with the following responsibilities:

- 1. Modifications **must** be submitted for review and approval before implementing the modification. This includes changes to study procedures, study materials, personnel, etc.
- 2. Data security procedures must follow procedures as approved in the protocol and in accordance with ITS <u>Guidelines for Data Handling</u>.
- Promptly notify the IRB (<u>uncc-irb@uncc.edu</u>) of any adverse events or unanticipated risks to participants or others.
- 4. Complete the Closure eform via IRBIS once the study is complete.
- 5. Be aware that this study is now included in the Office of Research Compliance (ORC) **Post-Review & Post-Approval Monitoring program** and may be selected for post-review monitoring at some point in the future.
- 6. Reply to ORC post-review monitoring and administrative check-ins that will be conducted periodically to update ORC as to the status of the study.

7. Three years (3) following this Exemption determination, ORC will request a study status update (active/not active).

Please be aware that approval may still be required from other relevant authorities or "gatekeepers" (e.g., school principals, facility directors, custodians of records).

CC:

Jan Warren-Findlow, Public Health Sciences

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OFFICE OF RESEARCH COMPLIANCE 9201 University City Boulevard 319 Cameron Hall Charlotte NC 28223-0001 (704)-687-1871 Web site: http://research.uncc.edu/ Federalwide Assurance (FWA) #00000649

To: Erin Thomas Public Health Sciences

From: Office of Research Compliance

Date: 9/26/2018 $\mathbf{RE}:$ Notice of Modification Approval (Exempt) Exemption Category 2. Survey, interview, public observation Study #: 18-0125

Study Title Qualitative exploration and measurement of body functionality among women with physical disabilities

This modification submission has been reviewed and approved by the Office of Research Compliance.

Submission Description:

I am adding a follow-up study. Based on the qualitative interviews conducted in this study, I have developed a pool of items to be considered for inclusion in a new measurement scale. This follow-up study involves recruiting subject matter experts to review the items in this pool for their content validity and relevance to the new construct being studied.

Investigator's Responsibilities:

- 1. It is the investigator's responsibility to promptly inform the committee of any changes in the proposed research, and of any adverse events or unanticipated risks to participants or others.
- 2. You are required to obtain Office of Research Compliance and/or IRB approval for any changes to any aspect of this study before they can be implemented. 3. Data security procedures must follow procedures as approved in the protocol and in accordance with
- ITS Guidelines for Data Handling.

Your approved consent forms (if applicable) and other documents are available online at http://uncc.myresearchonline.org/irb/index.cfm?event=home.dashboard.irbStudyManagement&irb_id=18-0125.

CC: Jan Warren-Findlow, Public Health Sciences



OFFICE OF RESEARCH COMPLIANCE 9201 University Citly Boulevard 319 Cameron Hall Charlotte NC 28223-0001 (704)-687-1871 Web site: http://research.uncc.edu/ Federalwide Assurance (FWA) #00000649

To: Erin Thomas Public Health Sciences

From: Office of Research Compliance

Date: 11/27/2018 RE: Notice of Modification Approval (Exempt) Exemption Category: 2.Survey, interview, public observation Study#: 18-0125

Study Title Qualitative exploration and measurement of body functionality among women with physical disabilities

This modification submission has been reviewed and approved by the Office of Research Compliance.

Submission Description:

I will be adding another study component, which I will call Study 3. In Study 3, I will recruit women with and without disabilities to provide online feedback about the relevance and importance of items on a new body image measurement scale.

Documents to be added in this modification include: 1) A recruitment message for social media; 2) an eligibility survey consent form (for waiver); 3) an eligibility survey; 4) email template to be sent to eligible participants; 5) a Delphi panel survey consent form (for waiver); 6) a Delphi panel "Round 1" survey; and 7) email template to remind participants to complete the survey before the closing date.

Investigator's Responsibilities:

- 1. It is the investigator's responsibility to promptly inform the committee of any changes in the proposed research, and of any adverse events or unanticipated risks to participants or others.
- 2. You are required to obtain Office of Research Compliance and/or IRB approval for any changes to any aspect of this study before they can be implemented.
- 3. Data security procedures must follow procedures as approved in the protocol and in accordance with ITS <u>Guidelines for Data Handling</u>.

Your approved consent forms (if applicable) and other documents are available online at http://uncc.myresearchonline.org/irb/index.cfm?event=home.dashboard.irbStudyManagement&irb_id=18-0125



OFFICE OF RESEARCH COMPLIANCE 9201 University City Boulevard 319 Cameron Hall Charlotte NC 28223-0001 (704)-687-1871 Web site: http://research.uncc.edu/ Federalwide Assurance (FWA) #00000649

To: Erin Thomas Public Health Sciences

From: Office of Research Compliance

Date: 1/09/2019 RE: Notice of Modification Approval (Exempt) Exemption Category: 2. Survey, interview, public observation Study#: 18-0125

Study Title Qualitative exploration and measurement of body functionality among women with physical disabilities

This modification submission has been reviewed and approved by the Office of Research Compliance.

Submission Description:

We are adding one more survey to the study. This survey will be the survey administered to Delphi panel participants for the second round. This is the last modification to be submitted under this approval.

Investigator's Responsibilities:

- 1. It is the investigator's responsibility to promptly inform the committee of any changes in the proposed research, and of any adverse events or unanticipated risks to participants or others.
- 2. You are required to obtain Office of Research Compliance and/or IRB approval for any changes to any aspect of this study before they can be implemented.
- 3. Data security procedures must follow procedures as approved in the protocol and in accordance with ITS <u>Guidelines for Data Handling</u>.

Your approved consent forms (if applicable) and other documents are available online at http://uncc.myresearchonline.org/irb/index.cfm?event=home.dashboard.irbStudyManagement&irb_id=18-0125.



OFFICE OF RESEARCH COMPLIANCE 9201 University Citly Boulevard 319 Cameron Hall Charlotte NC 28223-0001 (704)-687-1871 Web site: http://research.uncc.edu/ Federalwide Assurance (FWA) #00000649

To: Erin Thomas Deans Office College of Health and Human Services

From: Office of Research Compliance

Date: 3/02/2019 RE: Notice of Approval of Exemption with No End Date Exemption Category: 2. Survey, interview, public observation Study#: 19-0034

Study Title: Functional-Aesthetic Body Image Scale Validation

This submission has been reviewed by the Office of Research Compliance and was determined to meet the Exempt category cited above under 45 CFR 46.101(b). This determination has no expiration or end date and is not subject to an annual continuing review. However, you are required to obtain IRB approval for all changes to any aspect of this study before they can be implemented.

The Investigator Responsibilities listed below applies to this study only. Carefully review the Investigator Responsibilities.

Study Description:

We developed a new scale to measure functional-aesthetic body image, which is defined as a person's thoughts and feelings, and behaviors related to those thoughts and feelings, about their appearance while engaging in a variety of body functions. In this study, we aim to explore the scale's factor structure and psychometric properties to establish initial construct validity.

Your approved consent forms (if applicable) and other documents are available online at http://uncc.myresearchonline.org/irb/index.cfm?event=home.dashboard.irbStudyManagement&irb_id=19-0034.

Investigator's Responsibilities:

The above-cited determination has no expiration or end date and is not subject to annual continuing review.

However, the Principal Investigator needs to comply with the following responsibilities:

- 1. Modifications **must** be submitted for review and approval before implementing the modification. This includes changes to study procedures, study materials, personnel, etc.
- 2. Data security procedures must follow procedures as approved in the protocol and in accordance with ITS <u>Guidelines for Data Handling</u>.
- 3. Promptly notify the IRB (<u>uncc-irb@uncc.edu</u>) of any adverse events or unanticipated risks to participants or others.
- 4. Complete the Closure eform via IRBIS once the study is complete.
- 5. Be aware that this study is now included in the Office of Research Compliance (ORC) Post-Approval Monitoring program and may be selected for post-review monitoring at some point in the future.
- 6. Reply to ORC post-review monitoring and administrative check-ins that will be conducted periodically to update ORC as to the status of the study.

7. Three years (3) following this Exemption determination, ORC will request a study status update (active/not active).

Please be aware that approval may still be required from other relevant authorities or "gatekeepers" (e.g., school principals, facility directors, custodians of records).

CC: Charlie Reeve, Psychology

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APPENDIX B: MEASURES²

The Functionality Appreciation Scale (FAS)

Alleva, Tylka, & Kroon Van Deist, 2017 Used with permission from the author

- 1. I appreciate my body for what it is capable of doing.
- 2. I am grateful for the health of my body, even if it isn't always as healthy as I would like it to be.
- 3. I appreciate that my body allows me to communicate and interact with others.
- 4. I acknowledge and appreciate when my body feels good and/or relaxed.
- 5. I am grateful that my body enables me to engage in activities that I enjoy or find important.
- 6. I feel that my body does so much for me.
- 7. I respect my body for the functions that it performs.

Responses to each item range from 1 to 5, where:

1 = strongly disagree, 2 = disagree, 3 = neither agree nor disagree, 4 = agree, and 5 = strongly agree

² Licensed and/or copyrighted scales used in the present study are not included in this appendix. These scales include the Situational Inventory of Body Image Dysphoria-short form (Cash, 2002); The Appearance Evaluation and Appearance Orientation subscales of the Multi-dimensional Body-Self Relations Questionnaire (Brown, Cash, & Mikulka, 1990; Cash, 2018); the Body Image Disturbance Questionnaire (Cash, Phillips, Santos, & Hrabosky, 2004; and the World Health Organization's Disability Assessment Schedule 2.0, 12-item, self-administered version (Üstün, T. B., & World Health Organization, 2010). All scales were used with permission from the authors.

The Body Compassion Scale (BCS)

Altman, Linfield, Salmon, & Beacham, 2017 Used with permission from the author

HOW I TYPICALLY REGARD MY BODY

Please read each statement carefully before answering. To the left of each item, indicate how often you believe or behave in the stated manner, using the following scale:

Almost				Almost
never				always
1	2	3	4	5

- 1. When I wish some aspect of my body looked different, it feels like no one else understands my struggle.
- 2. When I think about my body's inadequacies, it tends to make me feel more separate and cut off from other people.
- 3. When I fail at some form of physical activity that's important to me, I tend to feel alone in my failure.
- 4. When I'm feeling physically uncomfortable I tend to obsess and fixate on everything that's wrong.
- 5. When my body isn't responding the way I want it to, I tend to be tough on myself.
- 6. I'm tolerant of my body's flaws and inadequacies.
- 7. I am tolerant of the way my clothes fit me.
- 8. When I feel my body is inadequate in some way, I try to remind myself that feelings of inadequacy are shared by most people.
- 9. I am accepting of the way I look without my clothes on.
- 10. When I feel frustrated with my body's inability to do something, I try to remind myself that most people in my condition feel this way at some point.
- 11. When I feel frustrated with my body's inability to do something, I tend to feel separate and cut off from other people.
- 12. When I notice aspects of my body that I don't like, I get down on myself.
- 13. I am accepting of my looks just the way they are.
- 14. When my body fails at something important to me I become consumed by feelings of inadequacy.

- 15. When I have physical symptoms, illness or injury, it tends to make me feel more separate and cut off from other people.
- 16. When I'm injured, ill or have physical symptoms, I remind myself that there are lots of other people in the world feeling like I am.
- 17. I try to see my body's failings as something everyone experiences in one way or another.
- 18. When I doubt my ability to do a new physical activity, I try to remind myself that most people also feel this way at some point.
- 19. When I am at my lowest during times of physical symptoms, illness or injury, I know I am not alone in feeling this way.
- 20. When I feel out of shape, I try to remind myself that most people feel this way at some point.
- 21. When I am frustrated with some aspect of my appearance, I try to remind myself most people feel this way at some time.
- 22. When I'm concerned if people would consider me good-looking, I remind myself that most everyone has the same concern.
- 23. I feel okay in my body.

Single-item Self-esteem Measure

Robins, Hendin, & Trzesniewski, 2001 Used with permission from the author

Please indicate the extent to which you agree with the following statement:

"I have high self-esteem."

O Strongly disagree

○ Somewhat disagree

 \bigcirc Neither agree nor disagree

 \bigcirc Somewhat agree

○ Strongly agree

APPENDIX C: FUNCTIONAL-AESTHETIC BODY IMAGE SCALE³

Functional-Aesthetic Body Image Scale

Instructions: The following questions are about how you think and feel about your appearance (including your body and face) when you are engaged in activities and movements. Examples of activities and movements include talking, laughing, walking, wheeling, and eating. Please indicate how strongly you agree or disagree with each statement by circling your chosen response to the right of the question. There are no right or wrong answers.

FABI-Self Items

1. I worry about how I look while I am exercising or doing physical activities.	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
2. I dislike seeing my reflection when I'm doing an activity (e.g., walking by a glass storefront, engaged in an activity in front of a mirror).	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
3. I worry that my body movements look awkward.	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
4. I compare the way <i>my</i> body looks while doing specific activities to how <i>others</i> ' bodies look while doing those same things.	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
5. I am self-conscious about the way I look during the physical act of eating or drinking, regardless of the food item or beverage.	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
6. I am concerned about how I look when I am talking and laughing with others.	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree

³ This version of the Functional-Aesthetic Body Image scale is the final iteration resulting from this research. The items are re-numbered to reflect the 22 item version and thus do not match the tables included in the dissertation text. Inquiries and requests for use should be sent to the author.

7. It is important to me that I appear as physically capable as possible.	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
8. I dislike how I look in my clothes when doing activities (e.g., walking, wheeling, exercising, sitting a certain way).	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
9. I worry about how other people evaluate what I look like when they see me moving.	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
10. Looking strong and functional is important to my overall sense of self.	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
11. I make efforts to look as smart or intellectually capable as possible.	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
12. I wear clothing items and/or shoes that are uncomfortable or restrict my movements because doing so helps me look good.	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
13. I am concerned about how my body looks during sex.	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
14. The things I do to enhance my appearance (e.g., how I style my hair, the way I dress) affect the functions and activities I can do.	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
15. Because of my body's functioning, I feel anxious about participating in social situations.	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
FABI-Other Items					
16. People make assumptions			Neither		

10. People make assumptions	Steenalry		Neither		Steenalt
about how my body works based	Disagraa	Disagree	Agree nor	Agree	Agree
on how I look.	Disagree		Disagree		Agree

17. The way people treat me is based on how I look when I'm doing specific activities.	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
18. My body movements look awkward to others.	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
19. Society's perception of me changes when they see my body in motion.	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
20. Other people might think I look good in a photo, but their perception of me would change if they saw me moving about in real life.	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
21. My relationships with others are influenced by how they see me doing specific activities.	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree
22. People notice how my body moves when I'm out and about.	Strongly Disagree	Disagree	Neither Agree nor Disagree	Agree	Strongly Agree