

# “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



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## ABSTRACT

A current hypothesis is that 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 visible physical disabilities (WPD), who have differences in body functionality and appearance that influence their body image. Our study aimed to understand how WPD conceptualize body image and body functionality and to clarify relationships between these constructs. We conducted semi-structured interviews with 15 women representing a range of ages (21–53 years) and disabilities. We used a constructivist grounded theory approach, applying the constant comparative method and engaging in reflexivity throughout the research process. 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.

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## Introduction

Body image, defined as a person’s thoughts, perceptions, and feelings about their body (Cash, 1990), is an increasingly prevalent topic of study among health researchers (Cash, 2017; Tylka, 2018). Although interest in the construct has flourished within the past three decades (Voelker, Reel, & Greenleaf, 2015), the body image experiences of underserved populations, such as people with disabilities, have not been fully explored in contemporary literature (Bailey, Gammage, van Ingen, & Ditor, 2015). 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], 2002). Globally, 15% of people have some form of disability (WHO, 2011); the prevalence among US adults is just over 25% (Okoro, Hollis, Cyrus, & Griffin-Blake, 2018). Physical disabilities (e.g., conditions in which activities of daily living are affected due to physical limitations or mobility restrictions) are the most common type among US adults and are more prevalent among women (19.2%) than men (12.0%) across the life span (Okoro et al., 2018; WHO, 2011).

*Visible physical disabilities* include disabilities that affect one’s physical functioning or mobility and are observable, perceptible, and/or evident to others (Goffman, 1963), due to either the nature of the condition or the use of mobility aids. Women with visible 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). Differences in the appearance of the body (e.g., observable muscle atrophy, visibly different body structures, and use of assistive devices such as wheelchairs and prosthetics; Gorgey & Dudley, 2007) are often inconsistent with dominant Western cultural body

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ideals for women, which emphasize a slender, “toned,” and youthful aesthetic and ultimately assume able-bodiedness (Heiss, 2011; Taub, Fanflik, & McLorg, 2003). Functional differences (e.g., mobility, reproductive/sexual function, and sensory issues) may also influence body image in this population (Nosek, Howland, Rintala, Young, & Chanpong, 2001).

Women with visible physical disabilities have not been explicitly included within the bulk of contemporary body image research, although the landscape may be changing with the increased interest in body functionality as a dimension of positive body image (Alleva et al., 2018). In prior research on body image and disability, women with physical disabilities represented various age groups and disabilities such as rheumatic conditions, post-polio, spina bifida, Parkinson’s disease, cerebral palsy, multiple sclerosis, fibromyalgia, and spinal cord injury (e.g., Alleva et al., 2018; Bailey et al., 2015; Caap-Ahlgren & Lannerheim, 2002; Gross, Ireys, & Kinsman, 2000; Hassouneh-Phillips & 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 women with physical disabilities may be related to other factors such as type of disabling condition(s) (i.e., acquired vs. congenital), time since acquiring disability, and specific conditions (Ben-Tovim & Walker, 1995; Gross et al., 2000; Trajano et al., 2010). Qualitative studies have drawn upon a range of philosophies, such as grounded theory approaches, phenomenology, and hermeneutic methods, 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 (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 & Lannerheim, 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).

The field of body image research has recently shifted 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 merely as physical abilities, as this would render the construct only relevant to non-disabled persons (Webb, Wood-Barcalow, & Tylka, 2015). Thus, the research community currently defines *body functionality* as everything the body *can do*, encompassing the body’s physical and mental skills, its health and internal processes, creative endeavors, self-care behaviors, 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 Deist, 2017).

*Body conceptualization theory* (BCT) purports that the human body is appraised regarding its aesthetic or appearance (“body-as-object”) or experienced as a functioning entity (“body-as-process”; Franzoi, 1995), providing the basis for the study of body functionality. Scholars have drawn upon BCT to explore differences in body image outcomes among men and women. Men are hypothesized to experience functionality-oriented embodiment (i.e., the ways in which the body inhabits the world; Piran, 2015, 2016, 2017); conversely, women are socialized to attend more to their appearance than their functionality (Franzoi, 1995). Other frameworks informing the study of body functionality include objectification theory (Fredrickson & Roberts, 1997; McKinley, 2011; McKinley & Hyde, 1996; Moradi, 2010; Moradi & Huang, 2008) and theories of embod-

iment (Menzel & Levine, 2011; Piran, 2015, 2016, 2017, 2019; Piran & Teall, 2012).

Research suggests that promoting a body functionality focus may reinforce positive body image outcomes (e.g., increased body appreciation, decreased self-objectification) among women (Alleva et al., 2014, 2015; Stern & Engeln, 2018). As such, scholars currently position body functionality as a sub-construct of positive body image and consider it antithetical to self-objectification (Abbott & Barber, 2010; Alleva et al., 2016; Fredrickson & Roberts, 1997; McKinley & Hyde, 1996; Menzel & Levine, 2011; Piran & Teall, 2012). Other contemporary research claims that viewing images of women’s bodies in functionality-focused positions may yield *negative* body image outcomes (Mulgrew & Hennes, 2015; Mulgrew & Tiggemann, 2018). The conflicting claims may be explained by differences in the studies’ experimental conditions. For example, Alleva et al. (2014) used an internally-oriented writing task whereas Mulgrew and Hennes (2015) and Mulgrew and Tiggemann (2018) used externally-oriented and idealized image exposure scenarios. Scholars later explored the effects of exposure to *non-idealized* functionality-focused video campaigns on appearance and functionality satisfaction (Mulgrew, McCulloch, Farren, Prichard, & Lim, 2018). Although post-video appearance satisfaction improved, viewing the campaign videos did not increase functionality satisfaction (Mulgrew et al., 2018). Further, effects were not maintained when participants viewed idealized images after watching the campaign videos (Mulgrew et al., 2018). Similarly, another study found that although engaging in positive writing reflections increased appearance and functionality satisfaction, reflections did not protect against viewing idealized images (Mulgrew, Stalley, & Tiggemann, 2017), suggesting the need for additional research exploring functionality and appearance themes. Researchers have called explicitly for more in-depth examinations of BCT (Mulgrew et al., 2018) and the construct of body functionality (particularly among individuals with limitations in function and visible differences; Webb et al., 2015) to clarify the appearance-functionality relationship.

Accordingly, Alleva and colleagues (2018) adapted an existing body functionality intervention to examine whether focusing on body functionality via three brief online writing exercises (i.e., *Expand Your Horizon*; Alleva et al., 2015) could improve body image outcomes among women with rheumatoid arthritis, who often experience functional and/or changes in their appearance related to their condition (Plach, Stevens, & Moss, 2004; Scott, 2014). Participants in the body functionality intervention group experienced improvements in body appreciation, body satisfaction, functionality appreciation, and depressive symptoms, compared to controls (Alleva et al., 2018). Effects were maintained at one-month follow-up (Alleva et al., 2018).

This recent research provides further quantitative support for the positioning of body functionality as a component of positive body image; however, complexities within the construct and its relationship to overall body image and appearance constructs have not been fully explored. Alleva et al.’s study (2018) was the first to study body functionality with women with functionality concerns, but the study focused on women with one disability type. It is important to explore these concepts with women with a range of disabilities (e.g., those with congenital and acquired disabilities and with varying conditions). Qualitative inquiry may be particularly useful to elucidate the full construct space of body functionality within this population. Therefore, 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 aimed to (a) understand how women with a range of acquired and congenital disabilities and demographic backgrounds define and experience body image and body functionality, and (b) explore how body functionality

contributes to body image among women with visible physical disabilities.

## Method

### Study context

In addition to the theoretical underpinnings driving the research aims, the design and implementation of and context for the study were further informed by the principles of universal design for research – an implementation approach that allows for the inclusion of the broadest possible populations while minimizing the need for specific modifications (Williams & Moore, 2011). We strived to design and conduct a study that curtailed barriers to participation in qualitative research. For example, we conducted the majority of interviews using video-interfacing technology (e.g., Skype and FaceTime) to reduce environmental barriers.

### Study design

In this study, we used a constructivist grounded theory approach (Charmaz, 2006). Traditional grounded theory methodology emphasizes the discovery of emerging patterns from and generation of theories that are “grounded” in the data and requires 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 a predominant focus on theory generation as the end product (Glaser & Strauss, 1967). *Constructivist* grounded theory also emphasizes the role of researcher-participant relationships in co-constructing the grounded theory and thus necessitates that researchers engage in reflexivity throughout the research process (Charmaz, 2000, 2006; Mills, Bonner, & Francis, 2006).

We used semi-structured interviews conducted via Skype, FaceTime, or phone to gather participants’ perspectives. The semi-structured nature of the interview guide allowed participants more control over the flow of the interview and helped to ensure participants shared experiences they found relevant to the concept (Patton, 2002).

### Participants

Those eligible for the study identified as women in a way that was meaningful for them, experienced a visible physical disability, lived in the US, could express themselves using Standard English, and were between the ages of 18 and 55. We recruited only women for the present study primarily because the research exploring whether focusing on body functionality improves body image currently focuses on women’s experiences (Alleva et al., 2014, 2015, 2016, 2018; Mulgrew & Hennes, 2015; Mulgrew & Tiggemann, 2018; Mulgrew et al., 2018; Stern & Engeln, 2018). The upper age limit of 55 was set to explore the research questions with women with disabilities that were not primarily due to aging. Although the experience of disability *can* be considered a feature of “normal” aging (e.g., most people will experience a disability at some point in their lives as they age; Garland-Thomson, 2016), disability scholars and activists have reinforced the importance of distinguishing the experiences of disability from those of aging (Edison & Notkin, 2009).

The sample consisted of 15 women. This sample size was determined sufficient due to our reaching theoretical saturation (Charmaz, 2006); it also meets guidelines suggested by Patton (2002) to allow for the exploration of trends within and between qualitative research participants. Consistent with constructivist approaches, we purposively sampled participants to represent the heterogeneity of the population of women with visible physical

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 conditions) and other characteristics of identity (see Table 1).

In summary, participants ( $M_{\text{age}} = 33.3$ ) identified as having acquired and/or congenital disabilities, with the most common acquired condition being spinal cord injury and the most common congenital condition being cerebral palsy. Six participants had more than one disability; secondary disabilities included chronic medical conditions, cognitive disability, learning disability, mental health disability, speech-language disability, and visual impairment. The majority of the sample (73.3%) identified as white. Participants were relatively highly educated, with 46.7% holding an advanced (master’s or doctoral) degree.

### Research team

The research 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 identified as having disabilities. The lead author conducted all interactions. At the time of data collection, the lead author was a 31-year old, White, female doctoral candidate with training in public health and neuroscience and six years of experience working with people with disabilities. At the time of the study, the lead author did not identify as having a disability.

### Procedure

Participant recruitment began after we obtained ethical approval from the University of North Carolina at Charlotte’s institutional review board. The first author created a Facebook post on her personal page; regional and national disability researchers and advocacy groups subsequently shared the post with their audiences. The recruitment announcement indicated the study was about “body image and health for women with physical disabilities.” This recruitment information was also shared on several academic disability Listservs. Interested participants were directed to an eligibility survey. All eligible participants were emailed to schedule an interview. We conducted interviews between May and August of 2018. We used FaceTime or Skype video calls for interviews when possible. Accommodations were offered to promote rapport. Two participants completed audio-only interviews due to disability-related challenges placing and using the camera on their mobile phones without assistance.

Interviews began with a review of the informed consent form. Participants gave verbal consent to participating in the interview and having their words audio-recorded, and then chose their own pseudonyms to help establish rapport (Allen & Wiles, 2015); many participants, unprompted, discussed the name choice process which allowed the interviewer to demonstrate reflective listening and engage in pre-interview conversation unrelated to the interview topic. All interviews began with a “grand tour” question (Spradley, 1979) to further build rapport. The interviewer accommodated the flow of the dialogue by adding questions and/or asking questions out of order. Audio, but not video, was recorded in all cases. Interviews ranged in length from approximately 18 to 55 min ( $M = 37:19$ ). Participants received \$20 Amazon.com e-gift cards for completing the study.

### Materials

#### Eligibility survey

This survey collected each potential participant’s age, gender identity, race/ethnicity, disability status and type, educational

**Table 1**  
Participant characteristics.

Pseudonym	Age	Race/ethnicity	Disability type	Disability diagnoses <sup>a</sup>	Education level	Interview 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-American	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

<sup>a</sup> Information presented using the terms provided by participants to describe their disability(ies).

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 either failed to respond to the interview 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 eligibility survey after data saturation was reached but before the survey was closed; they were offered participation in a related separate study.

#### Interview guide

We developed interview questions and prompts (see Table 2) based on relevant domains of objectification theory and BCT (e.g., appearance surveillance and attention to body functionality; Franconi, 1995; Fredrickson & Roberts, 1997; McKinley & Hyde, 1996) and those of feminist disability theory (e.g., the ways in which their disability-related identities and experiences influence their ideas about body image; Garland-Thomson, 2002). Sample questions included, “What does the term “body image” mean to you?”, “What about your body do you like the most/least?”, and “How might you describe the relationship between appearance and body functionality?” Sequencing guidelines set forth by Spradley (1979) further informed the protocol. We designed prompts and sub-prompts to allow for more thorough exploration and discussion of emerging concepts. Question 8 (“What does the term, ‘body functionality’ mean to you?”) was added to the interview guide after the eighth interview. This question was added in response to an interview during which the participant, unprompted, offered her definition of body functionality. The revision of the interview guide throughout the data collection and analysis process is consistent with grounded theory (Chiovitti & Piran, 2003).

#### Analysis

The lead author verbatim-transcribed recordings within 72 h of interview completion. Handwritten notes taken during interviews and reflexive journals written immediately following interviews were also typed. After transcribing, the lead author engaged in “pre-coding” (Saldaña, 2016), by reading interview transcripts and highlighting notable quotes and phrases. Transcripts were uploaded to QSR International’s NVivo 12 software for coding and analysis.

Consistent with the formative literature on grounded theory, we used inductive in vivo coding in the first cycle coding process, retaining participants’ original words and phrasing to generate a codebook, used primarily to organize and keep record of codes and their evolution (Charmaz, 2008; Miles, Huberman, & Saldaña, 2014). The first and second interviews were coded and the initial codebook developed based on in vivo codes from these two interviews. Focused and descriptive coding approaches were used in the second cycle to categorize and merge similar codes within and across interviews. Data collection and analysis then followed the constant comparative method (Glaser & Strauss, 1967): transcripts were coded and then compared with all previous interviews and with the codebook. The codebook was revised between each interview to reflect the emergence of new codes, revision of existing codes, merging of multiple codes, categorizing of codes, and deletion of codes that faded out (Charmaz, 2008) until saturation was reached. Themes and subthemes were extracted based on their emergence across cases and their explanatory value within cases. Extraction and naming of themes and subthemes was based on participant’s words and phrasing and themes found in similar prior research (Bailey, Gammage, & van Ingen, 2017; Caap-Ahlgren & Lannerheim, 2002). We used diagramming (Buckley & Waring, 2013) to illuminate intersections of codes and themes to develop a preliminary conceptual model. Data collection was determined to be sufficient when theoretical saturation was reached (Charmaz, 2006; Glaser, 2001). We used Glaser’s (2001) definition to guide our assessment of saturation; we ceased data collection when the constant comparison of participants’ words and experiences yielded no new conceptual patterns.

#### Data presentation

We present quotations in this manuscript in the exact manner in which participants spoke them. We did not correct participants’ grammar, delete or change words, or delete filler phrases (e.g., “um,” “uh,” “you know?”) from their quotations. Scholars have interpreted some fillers as serving important dialectical functions. For example, “you know?” may be interpreted as a participant’s request for a sign of understanding, and can be indicative of comfort with the interviewer (DeVault, 1999; Warren-Findlow, 2006). Likewise, uses of “um” and “uh” may indicate a participant is searching for a certain word or phrase or is deciding what to say next (Clark & Fox Tree, 2002). We removed the interviewer’s fillers for brevity and readability.



**Table 2**  
Semi-structured interview guide.

Order	Question	Sample prompts
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 <i>this</i> 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 you think about your body? Is it about how others 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	So, I'm hearing you talk about how your body looks or appearance (or) the things your body does. I wonder if you might talk a bit about things your body <i>does</i> (or) 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? <sup>a</sup>	
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?	

<sup>a</sup> This question was added to the interview guide after the eighth interview was completed, so only a subset of participants responded.

### Methodological and interpretive rigor

We incorporated several methods to demonstrate the study's methodological and interpretive rigor (Chiovitti & Piran, 2003; Cooney, 2011). To enhance the study's *credibility*, we provide evidence of reflexivity to articulate how the lead researcher's insights influenced the research process and show that participants guided the inquiry (e.g., the interview guide was revised to reflect concepts offered by participants). We rely on participant quotations to represent themes and include their words within the resulting theory. We also conducted member checks; within 10 days following their interview, participants received a 2- to 3-paragraph summary of the discussion and were asked to confirm or correct it. We used summaries to allow the participants to check our preliminary *interpretations* of their accounts, rather than simply checking the accuracy of the transcript. One participant requested to add a sentence reflecting her partner's positive influence on her body image. Another participant pointed out a typing error. All others were confirmed by participants without revision. Lastly, we used multiple coders; the second author was provided a clean copy of the codebook and relevant transcript for coding two interviews early in the data collection process. The coders met for peer debriefing meetings (Lincoln & Guba, 1985) during which the coding, analysis, and theorizing done by the first author were discussed with and challenged by the second author. The coders agreed on the final themes and subthemes.

To demonstrate the study's *auditability*, the first author maintained an audit trail of all study decisions by keeping field notes, practicing reflexivity, and writing memos to document methodological and analytical decisions (Chiovitti & Piran, 2003). To demonstrate the study's *fittingness* (or transferability), we provide detailed contextual data, such as participant characteristics, and describe the purposive sampling design (Cooney, 2011).

### 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, with support from direct quotations from participants.

### Meanings and definitions

#### Body image

Early in the interviews, we asked participants to describe what the term “body image” meant to them. Overall, participants defined body image holistically, including internal and external views of the body, recognizing positive and negative aspects, and encompassing appearance and body functionality domains. Few participants endorsed stereotypical opinions about body image, such as that it is a women's issue or that it focuses solely on weight and body size. Body image definitions did not differ based on disability type.

*Body image is comprised of internal and external perspectives.* All participants included some statement in their definition of body image about how a person sees or feels about their body, or some variation of an *internal* perspective of one's own body. Ten women also defined body image as how someone else or broader society sees their body, indicative of self-presentation. Chloe, 36, with cerebral palsy, 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, 29, with a leg amputation, similarly emphasized the importance of self-presentation, or the *external* view of the body:

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, 39, with cerebral palsy and a visual impairment, provided a definition of body image that included these 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, 27, who uses a prosthetic leg, indicated:

Right now, I feel good about myself. . . there are days where I am just as negative as the next person, but then it's so much easier now for me to get out of those moments than it was three to five years ago.

*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. Bobbi, 36, with multiple physical and neurological disabilities, explained: "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, 28, who acquired her spinal cord injury and chronic medical condition 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 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, 21, a college student with multiple physical and medical disabilities, described body image as "usually" a women's issue.

#### *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, 29, who experienced a recent spinal cord injury) and "the mechanics of the body and how it all works together" (Silver, 53, with cerebral palsy and a learning disability) in their definitions. Catherine, 30, with spina bifida, 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, 40, who experienced spinal cord and traumatic brain injuries resulting in physical and cognitive disabilities, 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:

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 (30, with cerebral palsy) and Kasey (48, with a spinal cord injury) both initially responded by saying, "It depends on the day!" Nine women described experiencing "fluctuations" or variations concerning their body image. When prompted further, participants described how their body image often aligned with their health symptoms.

#### *Health symptoms*

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

*Mental health symptoms.* Mental health symptoms emerged as a notable 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 explained: "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:

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 changes 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 these symptoms, 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 negatively affected her body image:

I have been dealing with. . .this rare lung condition that was just diagnosed about a month ago, even though the symptoms have been occurring for close to two years. . . 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 participants described 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, those factors are presented 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:

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?

Similarly, Kasey revealed: "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.* Six women described upward and downward body functionality comparisons with others. Grace said, "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 functionality comparisons:

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.

Participants also made upward comparisons to able-bodied women and described a functional ideal to which they compare themselves; these discussions tended to relate 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:

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 women mentioned facial features including their eyes, smiles, and 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:

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 and most frequently endorsed 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 body functions. 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 interaction of appearance and body functionality.

#### *Eating*

Two participants described how their appearance while eating was a substantial concern, despite describing themselves as having an overall positive body image. Tammy, 27, with cerebral palsy, 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 she is self-conscious about her "oral-motor issues."

#### *Clothing and dressing*

Participants 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" as a way to stand out 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 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 discussed how her functional challenges influence 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 a double-edged sword:

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 accessing adaptive clothing and accessories influenced her body image:

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 appearance-related factors intrinsically linked to their body functionality that influenced their body image, usually negatively. Participants related changes in their weight, body size, or body composition to their disabilities. Kristen described such changes:

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, 27, with a spinal cord injury, described how she and other women with physical disabilities discuss specific body 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). While integral to their bodies' functionality, participants were also aware of how an ableist society perceives these aids. Tammy discussed how experiencing this 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 being self-conscious about using 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 how she proves 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

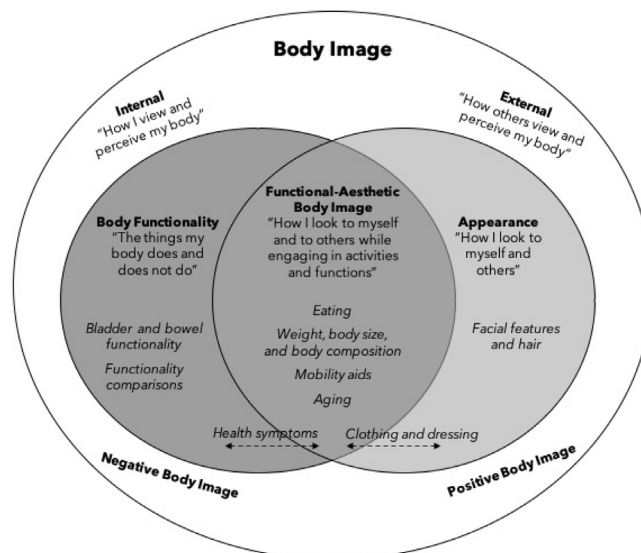


Fig. 1. Conceptual model developed from study findings, adapted from Franzi's (1995) body conceptualization theory.

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. For example, Kasey noted:

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 expressed similar concerns: "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."

#### Conceptual model

We developed a preliminary conceptual model (see Fig. 1) from study findings. Each emergent theme and subtheme is represented 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* domains. Sub-themes that emerged independently under appearance (e.g., *facial features and hair*) and body functionality (e.g., *bladder and bowel*



function and functionality comparisons) are listed in those respective domains, outside of the overlapping domain. Subthemes described by participants as representing functional-aesthetic body image (e.g., *eating; weight, body size, and body composition; mobility aids; and aging*) are centered within that domain. The *health symptoms* subtheme is placed 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

Our study used a constructivist grounded theory approach to explore meanings of and experiences with body image, with an emphasis on body functionality, among women with a diverse range of visible physical disabilities. Our study is consistent with research exploring body image among individuals with spinal cord injury (Bailey, Cline, & Gammage, 2016). Women in the present study provided definitions of body image that incorporated internal and external perspectives. Participants in the present study similarly did not demonstrate any beliefs that internal (body image) and external (self-presentation) perspectives were distinct concepts. It is not surprising that participants in the present study would include self-presentation, or "impression management," in their definitions of body image (Bailey et al., 2016; Leary & Kowalski, 1990) given the *visibility* of their disabilities and the related treatment by others they described.

Women in the present study, like participants in a study exploring body image among members and trainees of an exercise facility for people with disabilities and chronic conditions (Bailey et al., 2017), also held holistic definitions of body image, indicating body image is both positive and negative, and emphasizing a focus not only the appearance of the body, but its functionality. Participants in our study supported the idea that both positive and negative body image can be context-dependent states that fluctuate temporally and with health and disability symptomatology. This finding is consistent with previous qualitative research exploring body image among people with disabilities and health conditions (Bailey et al., 2015; Pearce, Thogersen-Ntoumani, Duda, & McKenna, 2014; Posen et al., 2000; Sheldon, Renwicz, & Yoshida, 2011) and quantitative research with other populations (e.g., Albertson, Neff, & Dill-Shackleford, 2015), providing additional evidence that positive and negative body image are not solely stable traits (Tylka & Wood-Barcalow, 2015). A third of participants in the present study explicitly described body image as incorporating appearance and body functionality, without any prompt to discuss functionality. We theorize that the experience of visible physical disability *necessitates* a focus on body functionality within overall body image, because individuals with visible disabilities literally *experience their function* as part of their overall appearance.

In addition to confirming previous research, our study extends the literature in two main ways: first, our results add considerably to body image theory by suggesting an expansion of the currently accepted definition of body functionality and challenging its theoretical positioning. Second, our study informs practice by illuminating complex relationships between appearance and body functionality that may be useful to address within body image interventions.

## Theoretical implications

The present study extends existing literature (Bailey et al., 2015, 2017; Wood-Barcalow, Tylka, & Augustus-Horvath, 2010) exploring definitions of body image by also eliciting definitions of body functionality. Participants believed body functionality encompasses a range of bodily processes and does not solely focus on physical abilities, partially supporting the research community's current definition. Participants also offered additional perspectives that support reevaluating the definition and theoretical placement of the construct. For example, participants in our study indicated that the definition of body functionality should recognize what some bodies *cannot* do, and that many bodies function *differently*. Our findings also indicate that body functionality is frequently linked to negative body image among women with visible physical disabilities. Emphasizing solely what the body *can* do, and considering functionality 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; Mulgrew & Tiggemann, 2018; Shakespeare & Watson, 2001).

Our most notable finding was the emergence of the functional-aesthetic body image concept, which describes people's thoughts and feelings, and behaviors resulting from those thoughts and feelings, about their appearance while they are engaged in body functions. Our study findings about functional-aesthetic body image yield a critical theoretical development that challenges the object-process dichotomy (Wasylikiw & Butler, 2014). Previous research has discussed the importance of considering both functional and aesthetic perspectives within body image research (Abbott & Barber, 2010); however, our study is the first of which we are aware to find empirical evidence of the overlap of these constructs. This development may help further explain the mixed results of previous studies assessing whether focusing on body functionality can promote positive body image outcomes among women (e.g., Alleva et al., 2014; Mulgrew & Hennes, 2015; Mulgrew & Tiggemann, 2018) and inform the design of future research. For example, it would be useful to test whether focusing solely on internal body processes that cannot be or are not usually visible to others elicits more positive body image outcomes.

The study's conceptual model also makes a unique theoretical contribution. BCT has informed much conceptual and empirical research in the field (e.g., Ghaznavi & Taylor, 2015; Mulgrew & Hennes, 2015; Mulgrew & Jeffrey, 2019; Mulgrew, Johnson, Lane, & Katsikitis, 2014; Mulgrew & Tiggemann, 2018; Webb et al., 2019), yet scholars have not fully developed the dimensionality of the *function* and *appearance* domains comprising BCT nor offered a specific framework describing how these domains may overlap. The current model offers clear categorizations of concepts that women in the study described as relating to their body functionality, appearance, or an intersection of the two constructs. This development may prompt researchers to explore further additional domains of the concepts of body functionality, appearance, and functional aesthetic body image to further refine theory and drive the development of body image interventions.

## Implications for practice

Present study findings provide impetus to adapt existing body image programs or develop new body functionality-focused interventions (Alleva et al., 2014, 2018). Programs that teach women to focus on and appreciate internal or *invisible* body functions rather than *visible* functions to enhance body image outcomes may be more effective across broad groups. Concepts presented in the conceptual model (Fig. 1) as being linked to body func-

tionality but not to functional-aesthetic body image (e.g., bladder and bowel functionality) may serve as an initial area of focus in future interventions. Researchers might also refrain from asking women to focus on certain aspects of their body functionality that overlap with appearance concerns, for example, digestion (Alleva et al., 2015; Avalos & Tylka, 2006). Although digestion is not a visible body function, it relates to eating, which was identified as a functional-aesthetic concern for many women. It may also be useful to explore how different groups conceptualize the visibility of body processes to bolster intervention effectiveness; for example, people possessing “typical” functionality might consider bladder and bowel function a solely internal process, whereas people who have stomas or use catheters may differently evaluate this experience.

Study findings may also inform interventions designed to enhance body image specifically among women with disabilities. For example, given the evidence that people with disabilities include self-presentation within their definitions of body image, effective body image interventions for this population and others with visible differences might consider also addressing body image resilience (Hensley-Choate, 2011) and/or coping mechanisms for experiencing disability- and appearance-related stigma and discrimination.

### Reflexivity

In keeping with the traditions of constructivist grounded theory and as the lead author who conducted and analyzed all of the interviews, I engaged in reflexivity throughout the process to document how my identities, training, and life experiences may have influenced the research (Findlay, 2002). My identity and training as a feminist social constructionist researcher influenced the design of the study, implementation of interviews, and analytic processes. “Nothing about us without us” is a common phrase shared in the disability rights movement (Charlton, 1998). Working within a constructivist framework allows me to fully embrace this sentiment, emphasizing the lived experiences of community members and retaining their words and phrases in generating knowledge about issues that affect their well-being.

In my experiences working with individuals with disabilities, I have received formal and informal training on “disability etiquette.” There were times during the interviewing process that I felt this etiquette may have prevented me from asking detailed questions about participants’ conditions (e.g., asking how an injury happened) because I did not want to offend participants and risk losing their trust. It is possible that someone who has received less of this training or is not as familiar with topics that are considered unacceptable to discuss may have uncovered more detailed information about participants’ conditions and experiences.

It is important to note that I have ingrained privileges, as a young woman without any current visible disabilities, which may have further influenced the interview process. Women in the study may not have disclosed specific topics with me, or may have used different language with me, due to the fact that I identify as temporarily able-bodied. I had the advantage of recruiting participants through my and another research team member’s connections to established and trusted community members, which helped build trust and rapport. My privileged position as an academic from a middle-class background may have also influenced interviews. I reflected halfway through the 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. Most of the participants in my study were highly educated, so this may have been less of an issue, but the revelation certainly informed future studies I might conduct.

### Limitations and future directions

Study results should be interpreted with considerations. Only half of the participants were asked to define body functionality. Although we reached saturation on this question, it is possible that transferability of this finding could be limited, in that a more heterogeneous sample (e.g., including people with other types of disabilities or no disabilities, men, etc.) might offer different definitions of the body functionality construct. We therefore encourage researchers to conduct additional studies focused on elucidating the definition and domains of body functionality among individuals with disabilities and within broader populations, such as people who identify across gender, age, and ability spectra. Given the documented focus on body functionality over appearance among men (Franzoi, 1995; Piran, 2015) and recent evidence exploring male body image disturbance (e.g., Frederick & Essayli, 2016; Jankowski, Gough, Fawcner, Halliwell, & Diedrichs, 2018), exploring functional-aesthetic body image among men with disabilities may be a particularly ripe avenue for future research.

The present study was also limited by the use of only video and phone interviews. Particularly when working with people with disabilities, it may be important to offer choice of interview type and setting to accommodate the range of functional ability among participants. We recommend future qualitative studies with people with disabilities offer a broader range of interview types, such as in-person interviews where feasible and typing or chat-based interviews to make the qualitative research process more accessible to a broader range of potential participants (e.g., those who do not use verbal communication), enhance participant comfort, thereby building trust and rapport, and to more closely align with the principles of universal design for research (Kerschbaum & Price, 2017; Williams & Moore, 2011).

The use of web-based recruitment methods, a web-based eligibility survey, and interviews over video-conferencing or phone allowed only those women with access to Internet-enabled devices and an email address they regularly check to participate. This choice is likely to have resulted in our highly educated and relatively young (i.e., most between the ages of 20 and 30) sample; as such, women in our study may have higher levels of support and ultimately fewer challenges than those with lower socioeconomic status. Future studies should consider also using word-of-mouth and/or snowball recruitment strategies to access individuals representing a broader range of demographic backgrounds.

Lastly, we recommend that researchers collect and analyze demographic data about disability status and type, as they would data about gender identity, race, ethnicity, age, and socioeconomic status, within 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 commitment to diverse populations. This study emphasizes a need to include the perspectives of individuals with disabilities within research to expand the depth and breadth of the knowledge base regarding body image and related phenomena.

### Declarations of interest

None.

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## References

- Abbott, B. D., & Barber, B. L. (2010). Embodied image: Gender differences in functional and aesthetic body image among Australian adolescents. *Body Image*, 7, 22–31. <http://dx.doi.org/10.1016/j.bodyim.2009.10.004>
- Albertson, E. R., Neff, K. D., & Dill-Shackleford, K. E. (2015). Self-compassion and body dissatisfaction in women: A randomized controlled trial of a brief meditation intervention. *Mindfulness*, 6, 444–454. <http://dx.doi.org/10.1007/s12671-014-0277-3>
- Allen, R. E. S., & Wiles, J. L. (2015). A rose by any other name: Participants choosing research pseudonyms. *Qualitative Research in Psychology*, 13, 149–165. <http://dx.doi.org/10.1080/14780887.2015.1133746>
- Alleva, J. M., Diedrichs, P. C., Halliwell, E., Peters, M. L., Dures, E., & Stuijzand, B. G., et al. (2018). More than my RA: A randomised trial investigating body image improvement among women with rheumatoid arthritis using a functionality-focused intervention programme. *Journal of Consulting and Clinical Psychology*, 86, 666–676. <http://dx.doi.org/10.1037/ccp0000317>
- Alleva, J. M., Martijn, C. M., Jansen, A., & Nederkoorn, C. (2014). Body language: Affecting body satisfaction by describing the body in functionality terms. *Psychology of Women Quarterly*, 38, 181–196. <http://dx.doi.org/10.1177/0361684313507897>
- Alleva, J. M., Martijn, C. M., VanBreukelen, G. J. P., Jansen, A., & Karos, K. (2015). *Expand Your Horizon*: A programme that improves body image and reduces self-objectification by training women to focus on body functionality. *Body Image*, 15, 81–89. <http://dx.doi.org/10.1016/j.bodyim.2015.07.001>
- Alleva, J. M., Tylka, T. L., & Kroon Van Deist, A. M. (2017). The Functionality Appreciation Scale (FAS): Development and psychometric evaluation in U.S. community women and men. *Body Image*, 23, 28–44. <http://dx.doi.org/10.1016/j.bodyim.2017.07.008>
- Alleva, J. M., Veldhuis, J., & Martijn, C. (2016). A pilot study investigating whether focusing on body functionality can protect women from the potential negative effects of viewing thin-ideal media images. *Body Image*, 17, 10–13. <http://dx.doi.org/10.1016/j.bodyim.2016.01.007>
- Arzy, S., Overney, L. S., Landis, T., & Blanke, O. (2006). Neural mechanisms of embodiment: Asomatognosia due to premotor cortex damage. *Archives of Neurology*, 63, 1022–1025. <http://dx.doi.org/10.1001/archneur.63.7.1022>
- Avalos, L. C., & Tylka, T. L. (2006). Exploring a model of intuitive eating with college women. *Journal of Counseling Psychology*, 48, 486–497.
- Bailey, K. A., Cline, L. E., & Gammage, K. L. (2016). Exploring the complexities of body image experiences in middle age and older adult women within an exercise context: The simultaneous existence of negative and positive body images. *Body Image*, 17, 88–99.
- Bailey, K. A., Gammage, K. L., & van Ingen, C. (2017). How do you define body image? Exploring conceptual gaps in understandings of body image at an exercise facility. *Body Image*, 23, 69–79. <http://dx.doi.org/10.1016/j.bodyim.2017.08.003>
- Bailey, K. A., Gammage, K. L., van Ingen, C., & Ditor, D. S. (2015). "It's all about acceptance": A qualitative study exploring a model of positive body image for people with spinal cord injury. *Body Image*, 15, 24–34. <http://dx.doi.org/10.1016/j.bodyim.2015.04.010>
- Ben-Tovim, D. I., & Walker, M. K. (1995). Body image, disfigurement, and disability. *Journal of Psychosomatic Research*, 39, 283–291. [http://dx.doi.org/10.1016/0022-3999\(94\)00143-5](http://dx.doi.org/10.1016/0022-3999(94)00143-5)
- Buckley, C. A., & Waring, M. J. (2013). Using diagrams to support the research process: Examples from grounded theory. *Qualitative Research*, 13, 148–172. <http://dx.doi.org/10.1177/1468794112472280>
- Caap-Ahlgren, M., & Lannerheim, L. (2002). Older Swedish women's experiences of living with symptoms related to Parkinson's disease. *Journal of Advanced Nursing*, 39, 87–95. <http://dx.doi.org/10.1046/j.1365-2648.2002.02245.x>
- Cash, T. F. (1990). The psychology of physical appearance: Aesthetics, attributes, and images. In T. F. Cash & T. Pruzinsky (Eds.), *Body images: Development, deviance, and change* (pp. 51–79). New York, NY: The Guilford Press.
- Cash, T. F. (2017). *Body Image: A joyous journey*. *Body Image*, 23, A1–A2. <http://dx.doi.org/10.1016/j.bodyim.2017.11.001>
- Charlton, J. I. (1998). *Nothing about us without us: Disability, oppression and empowerment*. Berkeley, CA: University of California Press.
- Charmaz, K. (2000). Constructivist and objectivist grounded theory. In N. K. Denzin & Y. Lincoln (Eds.), *Handbook of qualitative research* (2nd ed., pp. 509–535). Thousand Oaks, CA: Sage.
- Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis*. London: Sage.
- Charmaz, K. (2008). Constructionism and the grounded theory. In J. A. Holstein & J. F. Gubrium (Eds.), *Handbook of constructionist research* (pp. 397–412). New York, NY: The Guilford Press.
- Chiovitti, R. F., & Piran, N. (2003). Rigour and grounded theory research. *Journal of Advanced Nursing*, 44, 427–435. <http://dx.doi.org/10.1046/j.0309-2402.2003.02822.x>
- Clark, H. H., & Fox Tree, J. E. (2002). Using *uh* and *um* in spontaneous speaking. *Cognition*, 84, 73–111. [http://dx.doi.org/10.1016/s0010-0277\(02\)00017-3](http://dx.doi.org/10.1016/s0010-0277(02)00017-3)
- Cooney, A. (2011). Rigour and grounded theory. *Nurse Researcher*, 18, 17–22. <http://dx.doi.org/10.7748/nr2011.07.18.4.17.c8631>
- DeVault, M. L. (1999). *Liberating method: Feminism and social research*. Philadelphia: Temple University Press.
- Edison, L. T., & Notkin, D. (2009). *Guest post: Disability and aging [blog]*. Retrieved from <http://disabledfeminists.com/2009/12/01/guest-post-disability-and-aging/>
- Findlay, L. (2002). "Outing" the researcher: The provenance, process, and practice of reflexivity. *Qualitative Health Research*, 12, 531–545. <http://dx.doi.org/10.1177/104973202129120052>
- Franzoi, S. (1995). The body-as-object versus the body-as-process: Gender differences and gender considerations. *Sex Roles*, 33, 417–437. <http://dx.doi.org/10.1007/BF01954577>
- Franzoi, S., & Shields, S. (1984). The Body Esteem Scale: Multidimensional structure and sex differences in a college population. *Journal of Personality Assessment*, 48, 173–178. [http://dx.doi.org/10.1207/s15327752jpa4802\\_12](http://dx.doi.org/10.1207/s15327752jpa4802_12)
- Frederick, D. A., & Essayli, J. H. (2016). Male body image: The roles of sexual orientation and body mass index across five national U.S. studies. *Psychology of Men & Masculinity*, 17, 336–351. <http://dx.doi.org/10.1037/men0000031>
- Fredrickson, B. L., & Roberts, T. A. (1997). Objectification theory: Understanding women's lived experience and mental health risks. *Psychology of Women Quarterly*, 21, 173–206. <http://dx.doi.org/10.1111/j.1471-6402.1997.tb00108.x>
- Garland-Thomson, R. (2002). Integrating disability, transforming feminist theory. *NWSA Journal*, 14, 1–32. <http://dx.doi.org/10.1353/nwsa.2003.0005>
- Garland-Thomson, R. (2016). *Becoming disabled*. *The New York Times*. Retrieved from <https://www.nytimes.com/2016/08/21/opinion/sunday/becoming-disabled.html>
- Ghaznavi, J., & Taylor, L. D. (2015). Bones, body parts, and sex appeal: An analysis of #thinpiration images on popular social media. *Body Image*, 14, 54–61. <http://dx.doi.org/10.1016/j.bodyim.2015.03.006>
- Glaser, B. (2001). *The grounded theory perspective: Conceptualization contrasted with description*. Mill Valley, CA: The Sociology Press.
- Glaser, B., & Strauss, A. (1967). *The discovery of grounded theory*. Chicago, IL: Aldine.
- Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity*. Englewood Cliffs, NJ: Prentice-Hall.
- Gorgey, A. S., & Dudley, G. A. (2007). Skeletal muscle atrophy and increased intramuscular fat after incomplete spinal cord injury. *Spinal Cord*, 45, 304–309. <http://dx.doi.org/10.1038/sj.sc.3101968>
- Gross, S. M., Ireys, H. T., & Kinsman, S. L. (2000). Young women with physical disabilities: Risk factors for symptoms of eating disorders. *Developmental and Behavioral Pediatrics*, 21, 87–96. <http://dx.doi.org/10.1097/00004703-200004000-00002>
- Hassounah-Phillips, D., & McNeill, E. (2005). "I thought I was less worthy": Low sexual and body esteem and increased vulnerability to intimate partner abuse in women with physical disabilities. *Sexuality and Disability*, 23(4), 227–240. <http://dx.doi.org/10.1007/s11195-005-8930-3>
- Heiss, S. N. (2011). Locating the bodies of women and disability in definitions of beauty: An analysis of Dove's campaign for real beauty. *Disability Studies Quarterly*, 31(1) <http://dx.doi.org/10.18061/dsq.v31i1.1367>
- Hensley-Choate, L. (2011). Toward a theoretical model of women's body image resilience. *Journal of Counseling & Development*, 83, 320–330. <http://dx.doi.org/10.1002/j.1556-6678.2005.tb00350.x>
- Jankowski, G. S., Gough, B., Fawker, H., Halliwell, E., & Diedrichs, P. C. (2018). Young men's minimisation of their body dissatisfaction. *Psychology & Health*, 33, 1343–1363. <http://dx.doi.org/10.1080/08870446.2018.1496251>
- Kerschbaum, S. L., & Price, M. (2017). Centering disability in qualitative interviewing. *Research in the Teaching of English*, 52, 98–107.
- Leary, M. R., & Kowalski, R. M. (1990). Impression management: A literature review and two-component model. *Psychological Bulletin*, 107, 34–47. <http://dx.doi.org/10.1037/0033-2909.107.1.34>
- Lincoln, Y. S., & Guba, E. G. (1985). *Naturalistic inquiry*. Beverly Hills, CA: Sage.
- McKinley, N. M. (2011). Feminist perspectives on body image. In T. F. Cash & L. Smolak (Eds.), *Body image: A handbook of science, practice, and prevention* (2nd ed., pp. 48–55). New York, NY: Guilford Press.
- McKinley, N. M., & Hyde, J. S. (1996). The Objectified Body Consciousness Scale: Development and validation. *Psychology of Women Quarterly*, 20, 181–215. <http://dx.doi.org/10.1111/j.1471-6402.1996.tb00467.x>
- Menzel, J. E., & Levine, M. P. (2011). Embodying experiences and the promotion of positive body image: The example of competitive athletics. In R. M. Calogero, S. Tantleff-Dunn & J. K. Thompson (Eds.), *Self-objectification in women: Causes, consequences, and counteractions* (pp. 163–186). Washington, DC: American Psychological Association.
- Miles, M. B., Huberman, A. M., & Saldana, J. (2014). *Qualitative data analysis: A methods sourcebook* (3rd ed.). Thousand Oaks, CA: Sage.
- Mills, J., Bonner, A., & Francis, K. (2006). Adopting a constructivist approach to grounded theory: Implications for research design. *International Journal of Nursing Practice*, 12, 8–13. <http://dx.doi.org/10.1111/j.1440-172X.2006.00543.x>
- Moradi, B. (2010). Addressing gender and cultural diversity in body image: Objectification theory as a framework for integrating theories and research. *Sex Roles*, 63, 138–148. <http://dx.doi.org/10.1007/s11199-010-9824-0>
- Moradi, B., & Huang, Y. P. (2008). Objectification theory and psychology of women: A decade of advances and future directions. *Psychology of Women Quarterly*, 32, 377–398. <http://dx.doi.org/10.1111/j.1471-6402.2008.00452.x>
- Mulgrew, K. E., & Hennes, S. M. (2015). The effect of functionality- and aesthetic-focused images on Australian women's body satisfaction. *Sex Roles*, 72, 127–139. <http://dx.doi.org/10.1007/s11199-014-0440-2>
- Mulgrew, K. E., & Jeffrey, A. (2019). Can image labels be used to reduce the impact of the muscular ideal in men? *Psychology of Men & Masculinities*, 20, 36–43. <http://dx.doi.org/10.1037/men0000140>
- Mulgrew, K. E., Johnson, L. M., Lane, B. R., & Katsikitis, M. (2014). The effect of aesthetic versus process images on men's body satisfaction. *Psychology of Men & Masculinity*, 15, 452–459. <http://dx.doi.org/10.1037/a0034684>



- Mulgrew, K. E., McCulloch, K., Farren, E., Prichard, I., & Lim, M. S. C. (2018). This girl can #jointhemovement: Effectiveness of physical functionality-focused campaigns for women's body satisfaction and exercise intent. *Body Image*, 24, 26–35. <http://dx.doi.org/10.1016/j.bodyim.2017.11.007>
- Mulgrew, K. E., Stalley, N. L., & Tiggemann, M. (2017). Positive appearance and functionality reflections can improve body satisfaction but do not protect against idealized media exposure. *Body Image*, 23, 126–134. <http://dx.doi.org/10.1016/j.bodyim.2017.09.002>
- Mulgrew, K. E., & Tiggemann, M. (2018). Form or function: Does focusing on body functionality protect women from body dissatisfaction when viewing media images? *Journal of Health Psychology*, 23, 84–94. <http://dx.doi.org/10.1177/1359105316655471>
- Nosek, M. A., Howland, C. A., Rintala, D. H., Young, M. E., & Chanpong, G. F. (2001). National study of women with physical disabilities: Final report. *Sexuality and Disability*, 19, 5–39. <http://dx.doi.org/10.1023/a:1010764703838>
- Okoro, C. A., Hollis, N. D., Cyrus, A. C., & Griffin-Blake, S. (2018). Prevalence of disabilities and health care access by disability status and type among adults – United States, 2016. *Morbidity and Mortality Weekly Report*, 67, 882–887. <http://dx.doi.org/10.15585/mmwr.mm6732a2>
- Patton, M. Q. (2002). *Qualitative research and evaluation methods* (3rd ed.). Thousand Oaks, CA: Sage.
- Pearce, G., Thøgersen-Ntoumani, C., Duda, J. L., & McKenna, J. (2014). Changing bodies: Experiences of women who have undergone a surgically induced menopause. *Qualitative Health Research*, 24, 738–748. <http://dx.doi.org/10.1177/1049732314529664>
- Perrier, M. J., Shirazipour, C. H., & Latimer-Cheung, A. E. (2015). Sport participation among individuals with acquired physical disabilities: Group differences on demographic, disability, and Health Action Process Approach constructs. *Disability & Health Journal*, 8, 216–222. <http://dx.doi.org/10.1016/j.dhjo.2014.09.009>
- Plach, S. K., Stevens, P. E., & Moss, V. A. (2004). Corporeality: Women's experiences of a body with rheumatoid arthritis. *Clinical Nursing Research*, 13, 137–155. <http://dx.doi.org/10.1177/1054773803262219>
- Posen, J., Moore, O., Sadah Tassa, D., Ginzburg, K., Drory, M., & Giladi, N. (2000). Young women with PD: A group work experience. *Social Work in Health Care*, 32, 77–91. [http://dx.doi.org/10.1300/J010v32n01\\_06](http://dx.doi.org/10.1300/J010v32n01_06)
- Piran, N. (2015). New possibilities in the prevention of eating disorders: The introduction of positive body image measures. *Body Image*, 14, 146–157. <http://dx.doi.org/10.1016/j.bodyim.2015.03.008>
- Piran, N. (2016). Embodied possibilities and disruptions: The emergence of the Experience with Embodiment construct from qualitative studies with women. *Body Image*, 18, 43–60. <http://dx.doi.org/10.1016/j.bodyim.2016.04.007>
- Piran, N. (2017). *Journeys of embodiment at the intersection of body and culture: The developmental theory of embodiment*. San Diego, CA: Elsevier. <http://dx.doi.org/10.1016/c2015-0-04666-4>
- Piran, N. (2019). The experience of embodiment construct. In T. L. Tylka & N. Piran (Eds.), *Handbook of positive body image and embodiment*. New York, NY: Oxford University Press.
- Piran, N., & Teall, T. (2012). The developmental theory of embodiment. In G. McVey, M. P. Levine, N. Piran & H. B. Ferguson (Eds.), *Preventing eating-related and weight-related disorders* (pp. 169–197). Ontario, Canada: Wilfrid Laurier University Press.
- Sands, R. T., & Wettenhall, R. S. (2000). Female wheelchair athletes and changes to body image. *International Journal of Disability, Development and Education*, 47, 413–426. <http://dx.doi.org/10.1080/713671149>
- Saldaña, J. (2016). *The coding manual for qualitative researchers*. Los Angeles, CA: Sage.
- Scott, D. G. I. (2014). What is RA? Retrieved from <https://www.nras.org.uk/what-is-ra-article#What%20isRA?>
- Shakespeare, T., & Watson, N. (2001). The social model of disability: An outdated ideology? In S. N. Barnartt & B. M. Altman (Eds.), *Research in social science and disability: Exploring theories and expanding methodologies* (pp. 9–21). New York, NY: Elsevier Science.
- Sheldon, A. P., Renwicz, R., & Yoshida, K. K. (2011). Exploring body image and self-concept of men with acquired spinal cord injuries. *American Journal of Men's Health*, 5, 306–317. <http://dx.doi.org/10.1177/1557988310375714>
- Spradley, J. P. (1979). *The ethnographic interview*. New York, NY: Holt, Rinehart and Winston.
- Stern, N. G., & Engeln, R. (2018). Self-compassionate writing exercises increase college women's body satisfaction. *Psychology of Women Quarterly*, 42, 326–341. <http://dx.doi.org/10.1177/0361684318773356>
- Taub, D. E., Fanflik, P. L., & McLorg, P. A. (2003). Body image among women with physical disabilities: Internalization of norms and reactions to nonconformity. *Sociological Focus*, 36, 159–176. <http://dx.doi.org/10.1080/00380237.2003.10570722>
- Trajano, R., Jorge, B., Brumini, C., Jones, A., & Natour, J. (2010). Body image in patients with rheumatoid arthritis. *Modern Rheumatology*, 20, 491–495. <http://dx.doi.org/10.1007/s10165-010-0316-4>
- Tylka, T. L. (2018). *Body Image: Celebrating the past, appreciating the present, and envisioning the future*. *Body Image*, 24, A1–A3. <http://dx.doi.org/10.1016/j.bodyim.2018.01.003>
- Tylka, T. L., & Wood-Barcalow, N. L. (2015). What is and what is not positive body image? Conceptual foundations and construct definition. *Body Image*, 14, 118–129. <http://dx.doi.org/10.1016/j.bodyim.2015.04.001>
- Voelker, D. K., Reel, J. J., & Greenleaf, C. (2015). Weight status and body image perceptions in adolescents: Current perspectives. *Adolescent Health, Medicine and Therapeutics*, 6, 149–158. <http://dx.doi.org/10.2147/AHMT.S68344>
- Warren-Findlow, J. (2006). Weathering: Stress and heart disease in African American women living in Chicago. *Qualitative Health Research*, 16, 221–237. <http://dx.doi.org/10.1177/1049732305278651>
- Wasylikiw, L., & Butler, N. A. (2014). Body talk among undergraduate women: Why conversations about exercise and weight loss differentially predict body appreciation. *Journal of Health Psychology*, 19, 1013–1024. <http://dx.doi.org/10.1177/1359105313483155>
- Webb, J. B., Vinoski Thomas, E., Rogers, C. B., Clark, V. N., Hartsell, E. N., & Putz, D. Y. (2019). Fitspo at every size? A comparative content analysis of #curvyfit versus #curvyvvyoga Instagram images. *Fat Studies*, 8, 154–172. <http://dx.doi.org/10.1080/21604851.2019.1548860>
- Webb, J. B., Wood-Barcalow, N. L., & Tylka, T. L. (2015). Assessing positive body image: Contemporary approaches and future directions. *Body Image*, 14, 130–145. <http://dx.doi.org/10.1016/j.bodyim.2015.03.010>
- Williams, A. S., & Moore, S. M. (2011). Universal design of research: Inclusion of persons with disabilities in mainstream biomedical studies. *Science Translational Medicine*, 3, 82cm12. <http://dx.doi.org/10.1126/scitranslmed.3002133>
- Wood-Barcalow, N. L., Tylka, T. L., & Augustus-Horvath, C. L. (2010). "But I like my body": Positive body image characteristics and a holistic model for young-adult women. *Body Image*, 7, 106–116. <http://dx.doi.org/10.1016/j.bodyim.2010.01.001>
- World Health Organization. (2002). *Towards a common language for functioning, disability, and health: ICF*. Geneva, Switzerland: World Health Organization.
- World Health Organization. (2011). *World Report on Disability 2011*. Malta: World Health Organization. Retrieved from <http://www.who.int/disabilities/world-report/2011/report.pdf>