Disability, Participation and Apparel throughout the Life Course

Jessica Dimka

Department of Anthropology, Temple University
Author contact: Jessica.dimka@temple.edu

Allison Kabel

Department of Health Sciences, University of Missouri
Author contact: kabela@health.missouri.edu

Kerri McBee-Black

Department of Textile and Apparel Management, University of Missouri
Author contact: Jmcbeeblackk@missouri.edu

Abstract

There are a growing number of people living with disabilities (PLWD) throughout the life course and across the disability spectrum. While much attention has been paid to environmental barriers to social participation for PLWD, apparel-related barriers have been largely overlooked. We conducted an online survey of 110 PLWD to identify challenges to finding appropriate clothing and related concerns regarding social participation for members of different adult age categories. Survey results included (1) difficulties finding or purchasing appropriate clothing and some apparel-related barriers to participation were more frequently reported by respondents in older age groups and (2) the increase in complications were not simply directly associated with aging.

Keywords: *Disability; aging; apparel; participation*

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Jessica Dimka

Department of Anthropology, Temple University

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Over 16% of Americans 21 to 64 years old and nearly half of people aged 65 and older are living with disabilities (Brault 2012). Further, the age structure of the United States' population is changing, with the proportion of the population aged 65 or older estimated to nearly double between 2012 and 2050 (Ortman, Velkoff, and Hogan 2014). From a strictly biomedical perspective, both disability and aging have significant impacts on individual- and population-level health and health care. However, neither disability nor aging are solely biological or biomedical characteristics or processes, as both are also strongly influenced by environmental and sociocultural factors. One such factor is clothing or apparel, which can affect, for example, expression or understanding of personal identity, mobility, social engagement, and treatment of or stigma against individuals in professional and personal arenas. Therefore, the interactions of age, disability and apparel are of particular interest to anthropologists and social scientists, as well as to health sciences researchers and health care providers.

The purpose of this study is to document the relationships among age, social participation and apparel for persons living with disabilities (PLWD). Specifically, we focus on how apparel can impact functioning and participation through the particular interactions of age and inadequate access to or availability of appropriate clothing. In the following sections, we first review literature on disability and social participation and anthropological perspectives on aging, disability and clothing. We then present survey results demonstrating that the interaction of these variables can be both a straightforward linear process of disability-related apparel concerns changing with older age, as well as a more complex issue in which personal and social desires and needs can factor into apparel and disability issues at any age.

Disability Assessment and Impacts on Social Participation

Different policy and research perspectives on disabilities have emphasized either individual limitations typically caused by disease or trauma that require medical care or intervention, or societal attitudes and

environmental barriers that exacerbate impairments. The World Health Organization, in creating the International Classification of Functioning, Disability and Health (ICF), recognized that an alternative model, which incorporates both these ideas as well as external environmental and internal personal factors, provides a more nuanced way of understanding disability. According to the ICF model, it is possible for all individuals, at different times, to experience some degree of temporary or permanent disability either because of health-related issues or because of the environment in which they live (World Health Organization 2002). Previous research has shown that apparel-related barriers can cause significant complications for PLWD, but also that these barriers transcend different clinical categories of disability and are often influenced by social attitudes and features of the built environment. These findings suggest that identifying and addressing clothing-related concerns may be best served with the ICF framework.

The ICF assesses health and disability at the level of the individual and of the population, and strategies for this assessment focus on functioning rather than disability, regardless of the particular reason for impairments in an individual's functioning. In addition to body functions and structures, the classification framework also considers required or desired activities or tasks, and participation or involvement in life situations and events. Assessments of individuals or populations thus identify impairments to body functions or structures, limitations to the ability to execute activities, and restrictions preventing participation. Together with the physical and social environment, these different aspects all contribute to what is commonly known as "disability" (World Health Organization 2002). Apparel-related concerns intersect all three components of the ICF framework. For example, clothing might need to be modified to allow access to IV ports or catheters necessitated by impairments in body function, or might interfere with the ability to use assistive devices and thus a person's ability to execute different activities (Banks 2001; Garner and Douglas 1991; Nessley and King 1980; Wang et al. 2014; White and Dallas 1977). Further, clothing can increase feelings of stigma that influence the desire or ability to engage in social participation (Carroll and Gross 2010; Carroll and Kincade 2007; Freeman, Kaiser, and Wingate 1985; Wingate, Kaiser, and Freeman 1986). For many PLWD, "…dressing in patient clothing can be a metaphor for illness or other health problems" (Topo and Iltanen-Tähkävuori 2010, 1685).

Social participation has been linked to a higher quality of life for people with disabilities throughout the life course (Jaeger, Röjvik, and Berglund 2015; Mikula et al. 2015), and physical as well as social environments are known to influence participation (Hammel et al. 2008). However, aging with disabilities has been associated with social disengagement (Kubina et al. 2013) and an increase in participation barriers that older adults must navigate (Johnson, Brown, and Knaster 2010). Strategies for coping with these barriers may become more difficult with age (Johnson, Brown, and Knaster 2010). For example, Twigg (2013) found that older adult women struggled to express themselves through clothing, as "the body could no longer perform in relation to dress in the ways it had in the past" (2013, 150). This struggle was due to the interplay between aging bodies and the "institutional biases" of the fashion industry, resulting in a lack of suitable apparel designed for and marketed toward older consumers (2013, 145).

Anthropological Perspectives on Aging, Disability and Clothing

Anthropological works reveal several points of intersection between aging, disability and apparel, including the dual role of social and physical or biological factors; the importance of identity and independence, particularly in light of the transient nature of health and ability across the life span; and issues of stigma and social participation. First, as indicated above, different conceptual models frame disability as either a biomedical impairment, a consequence of the social or built environment, or as with the ICF, both. Battles (2011) argues that one contribution of anthropology to disability studies has been a critique of the social model of disability, refining it to recognize the importance of the physical experiences of PLWD. An emphasis on the intersection of biology and culture highlights the possibilities of research integrating anthropological subfields to improve knowledge of disability across cultures and over time (Battles 2011; Sofaer 2006). Similarly, anthropologists have demonstrated the cultural values and assumptions, as well as the interactions between individuals and their environmental contexts, associated with aging, despite its common treatment in other fields as a culture-free biomedical process (Lamb 2014; Perkinson and Solimeo 2014). Anthropologists (e.g. Hansen 2004) also have discussed the embodied nature of clothing and the simultaneous individual and collective roles of such material items, coined the "social skin" by Turner (1993 [1980]). For example, the physical act of touching or holding apparel and accessories has even aided in recall of memories for people with dementia (Buse and Twigg 2015).

A second cross-cutting theme in anthropological research emphasizes personhood or identity and, in some cases, retention or loss of that identity as individuals transition to different age groups or health and ability statuses. For example, Lamb (2014) critiqued the "successful aging" model frequently espoused in the United States, which encourages independence and staying active, and presents an ideal vision of maintaining the self of a person's earlier years. This model, however, can be counterproductive by not encouraging individuals to accept the various changes that come with aging (Lamb 2014). Clothing choices are one way that identities may be maintained and expressed among individuals as they age. Research has shown, for example, that clothing has social and aesthetic significance for people with dementia, and selection of apparel consistent with styles preferred in the past may be one way for caretakers to cope with caring for elderly relatives (Buse and Twigg 2015). At all ages, disability can threaten perceived values of independence and identity, especially because individuals may easily become disabled at any time (Ginsburg and Rapp 2013; Reid-Cunningham 2009).

Sociocultural processes, historical context, and individual experiences all contribute to one's sense of self and how that identity is expressed through clothing (Twigg 2009). In some cases, individuals may actively embrace related changes, while for others, new apparel choices or needs may be resisted or rejected. For example, Stalp et al. (2009) explored the activities of members of the Red Hat Society, considering factors such as stigma associated with age and feminist issues of cultural norms about appropriate appearance and behavior in public, particularly for older women. These women dress in vibrant colors, may engage in loud, attention-grabbing behavior during group meetings, and aim to celebrate the aging process (Stalp et al. 2009). In their research on dress among individuals with dementia, Buse and Twigg (2015) note that while some clothing preferences and personal styles persisted into older age, it is also not uncommon for styles to change over time, which may cause conflict between the person and their caretaker, especially if the clothing choices are seen as inappropriate or indicative of the person's health condition.

Apparel issues related to stigma and social participation form another theoretical intersection among

anthropological works. In ethnographic interviews addressing opinions about the successful aging model described above, some individuals expressed discomfort with and a desire to be separated from others who might be perceived as unsuccessfully aging such as residents of nursing homes who may be noticeable through the use of wheelchairs or wearing of particular types of clothing such as bed clothes (Lamb 2014). Conversely, for the members of the Red Hat Society, choice of apparel encourages social participation and challenges stigmas about gender and age (Stalp et al. 2009). Disability studies similarly show that negative perceptions, potentially produced by the knowledge that anyone may become disabled, produce stigma and marginalization (Reid-Cunningham 2009). These barriers to social participation can be exacerbated or concealed by available clothing choices. In the work presented here, we conducted a survey particularly focused on apparel-related barriers to social participation, but responses reflect many of the above themes.

Methods

As part of a larger research project on clothing-related barriers (IRB protocol # 1210290), we conducted a survey aimed at PLWD and/or parents or caretakers of PLWD. The survey, hosted through Qualtrics.com, was distributed via social media platforms such as Facebook and faculty webpages. It was launched in March, 2014, and remained open until May, 2014. Respondents who completed the survey and provided sufficient contact information received an electronic gift card. No follow-up obligations were required of the participants.

All respondents were asked 37 questions, with up to 19 follow-up questions depending on their answers. Questions included, for example, whether individuals with disabilities experienced difficulty finding clothing with appropriate sizes and fit or that suited needs associated with the disability but also met standards of style and comfort, and whether respondents ever declined to participate in social activities, were concerned about employment prospects, or felt embarrassment due to the clothing available to them.

The results of the survey were explored to determine whether there were any age-related trends or whether particular concerns were more common with certain age groups. In this paper, we focus on respondents who are PLWD and may also be caretakers; we exclude participants who identified solely as caretakers. At this stage, only descriptive results are presented to indicate areas of concern that should be investigated with larger sample sizes and in more detail. Exemplary responses to open-ended questions are also included to illustrate the findings.

Results

At the time the survey was closed, a total of 240 surveys had been initiated. However, surveys that were incomplete or likely products of spamming were excluded from further analyses. Of the remaining surveys in the sample, 110 were completed by participants who identified as PLWD. Table 1 indicates the age group and sex reported by these respondents. Data on ethnicity and nature of disability were also collected but the analyses presented here pool all responses together for each age group to increase sample size. The majority of respondents in all age groups reported mobility-related challenges and white or European ancestry.

Table 1. Reported Demographic Data of PLWD Survey Participants

Age Group	Male	Female	Other	Total
18-24	5	3	0	8
25-35	15	16	0	31
36-49	13	23	0	36
50-64	8	21	1	30
65+	1	4	0	5
Total	42	67	1	110

The results reported here are drawn from the subset of the questions for which patterns or relationships with age could be discerned. Table 2 includes the full text of those questions and the possible responses, as well as the abbreviation used for each question throughout the rest of this paper. The two trends that became apparent were difficulties associated with increasing age and particular concerns associated with younger or intermediate age groups.

Table 2. Questions from Survey Demonstrating Age-Related Trends

Question	Possible Responses	Abbreviation
Have you encountered difficulty in finding appropriately sized clothing for yourself or the person for whom you provide care?	Never, Rarely, Sometimes, Routinely	Size
Have you encountered difficulty finding clothes that function to suit your needs but also meet (in terms of style, comfort, etc.) your standard of acceptability?	Never, Rarely, Sometimes, Routinely	Standards
Have you encountered difficulty in finding clothes with the appropriate fit (length, girth, overall fit)?	Never, Rarely, Sometimes, Routinely	Fit
Has your disability ever caused you (or your child/care recipient) to feel reluctant to try on clothes in a retail dressing room?	Never, Rarely, Sometimes, Routinely	Dressing Room Reluctance
Does your disability make it difficult for you (or your child/care recipient) to try on clothes in a retail dressing room?	Yes, No	Dressing Room Difficulty
Have you ever declined to participate in an activity, event or experience because you lacked or are unable to wear the required appropriate/acceptable clothing? For example, have you chosen not to attend a wedding or other formal occasion due to a lack of suitable formal attire or shoes/footwear?	Never, Rarely, Sometimes, Routinely	Participate
Are you able to find suitable swimwear for you or your child/care recipient?	Yes, No, I do not attempt to find swimwear	Swimwear
Do you have difficulty finding appropriate workout wear/athletic clothes?	Yes, No, I do not attempt to find this type of apparel	Exercise
Have you ever been concerned about barriers to employment due to required clothing?	Never, Rarely, Sometimes, Routinely	Employment

Has the lack of appropriate clothing ever caused you or your child/care recipient to miss out on something?	Never, Rarely, Sometimes, Routinely	Miss Out
Have apparel-related issues ever caused you embarrassment or humiliation?	Never, Rarely, Sometimes, Routinely	Embarrassment
Have apparel or clothing issues sometimes or routinely become a barrier in any of the following?	Romantic relationships, obtaining education or training, transportation (public or private), spending leisure time the way you would like	Romantic, Education, Transportation, Leisure

Trends with Increasing Age

Several questions demonstrated trends where difficulty with apparel increased or generally increased with age. For example, older respondents were more likely to respond "Sometimes" or "Routinely" (vs. "Never" or "Rarely") to statements that they experienced difficulty finding clothes with appropriate size or fit or that met their standards (Figure 1).
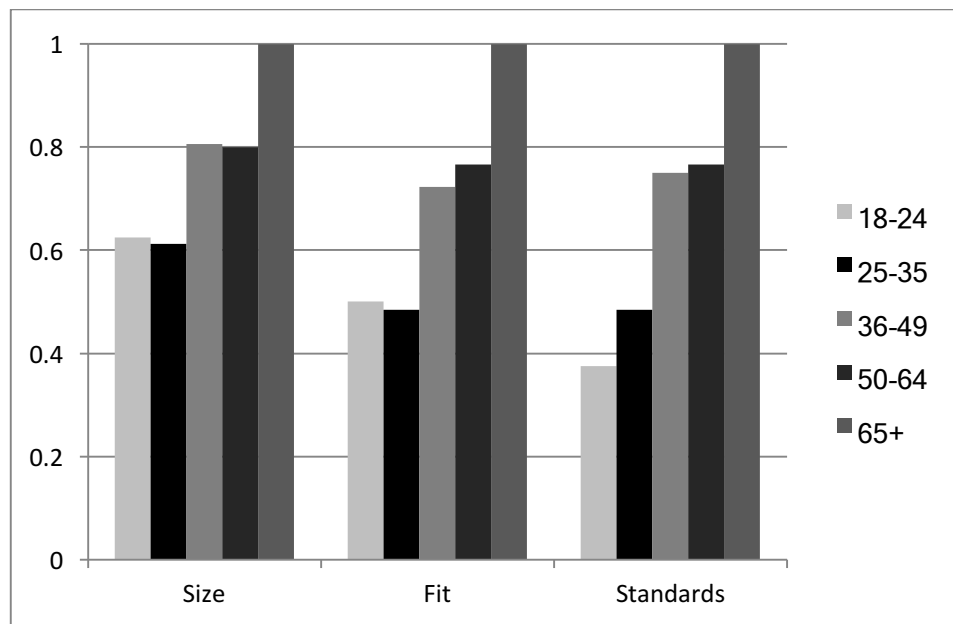
Figure 1. Proportion of Age Group Reporting "Sometimes" or "Routinely" to Indicated Questions

Despite varying degrees of reported difficulty, many of the specific complaints are similar across the age spectrum and reflect the need for clothing and apparel that both accommodate disability-related needs and are stylish and age-appropriate. For example, disabilities often result in atypical body sizes or proportions, leading to difficulty with finding appropriately fitting apparel items (Garner and Douglas 1991; Wang et al. 2014). Representative comments demonstrate these difficulties are shared and persistent across different age groups (Table 3). Another common problem for members of multiple age groups is difficulty with finding

appropriate shoes, as indicated by the example responses in Table 4.

Table 3. Representative Comments Regarding Difficulty with Clothing for Atypical Body Sizes and Shapes

Age Group	Representative Comments
18-24	"I'm small and wear a girls size 12/14 in clothes so it can be hard to find professional or age appropriate looking clothes sometimes."
25-35	"Pants are the hardest… I'm only 3f 7i and 30 years old. My rear end is bigger [than] what my leg length is!" "I'm 6′5 in a wheelchair, wide hips but skinny legs. Never have the right fit with pants."
36-49	"My arms & legs are very skinny due to loss of muscle tone so shirts & pants look very baggy on me." "…I have the size body of an adult but the height of a small child…"
50-64	"I am only 4 ft 4. All petite sizes must be hemmed for me. I cannot find pants (waist to hip measurement is too long). I have a barrel chest so need larger but shorter sizes."

Table 4. Representative Comments Regarding Difficulty with Shoes

Age Group	Representative Comments
18-24	"Shoes are hard to find due to them being hard to put on my prosthetic foot."
25-35	"Trouble finding shoes that fit my small feet that look professional and appropriate for a 30 year old. I also wear braces, so that makes it difficult too."
36-49	"Finding stylish shoes that I can walk in. Tennis shoes are best, but they aren't great for work or dressing up."
50-64	"Shoes that are wide enough to use with my brace for my right foot "Shoe size is preschool, finding adult styled shoes is nearly impossible."

Older respondents also reported increased difficulty using dressing rooms (38% in youngest age class and steadily increasing to 100% in the oldest), as well as increased reluctance to do so (25% in youngest, up to 100% in oldest). Answers to open-ended questions suggested these issues were frequently related to wheelchairs, braces, and other devices, which also produce issues with finding appropriate or desired clothing beyond dressing room concerns (Table 5). As mentioned above, the majority of respondents identified as having a mobility-related disability. However, reported difficulties also included perceptions of stigma from appearance or the presence of caregiver assistants in the room. One respondent wrote "People stare. It is hard enough to see me and how much something needs to be altered."

Table 5. Representative Comments Regarding Wheelchair-Related Apparel and/or Dressing Room Concerns

Age Group	Representative Comments
25-35	"Sometimes there are no dressing rooms large enough for a wheelchair and a caregiver whom I rely on for dressing assistance."
36-49	"Sizing, professional looking clothing that does not bunch up while sitting in a wheelchair all day, coats, sweaters, jackets, [blazers] that are not [too] long that I end up sitting on it and choking myself."
	"…I also have used a wheelchair my whole life so my thighs are thicker and my calves are skinny…"
	"I NEVER try on clothes in a dressing room. Not enough room inside for me & my helper & too time consuming. There's no way to transfer me in/out of my wheelchair to try on jeans/dresses/shorts with a lift being available."
65+	"Getting pants that come up higher in the back. Getting dress jackets that aren't too long for a person in wheelchair."
	"I use a scooter, space in the changing area. Few stores today have sales people available to get more. I cannot stand without my crutches."

Survey responses also demonstrate how clothing-related concerns can contribute to loss of social engagement and physical activity among older PLWD. Members of older age groups reported being more likely to decline to participate in social activities (the "Participate" question) because of clothing barriers. While only 13% of respondents aged 18-24 report this is sometimes or routinely a problem, 40% of respondents in both the 50-64 and 65+ age classes selected that response. Similar proportions for the different age groups indicated that clothing issues sometimes or routinely prevented them from spending leisure time as they would prefer. As above, however, additional details provided – in this case, the types of activities often cancelled or avoided – are similar across the age spectrum, with frequent examples including swimming events, graduation or wedding ceremonies and parties, sporting or exercise activities, and church services. One participant noted that the decision not to attend a wedding resulted in resentment and strain in a friendship, demonstrating how apparel-related decisions to participate can have long-lasting implications for social relationships. Conversely, the loss of social engagement due to disability can lead to changes in clothing choices and worsening emotions or health, as with one participant who described the frustration of being homebound and constantly wearing sleep- and loungewear.

Additionally, a few questions showed declining trends with age, most notably the Swimwear, Exercise and Transportation questions (Figure 2). Upon further examination, however, there is a corresponding general increase in the proportion of each age category who stated they do not attempt to find swimwear or athletic apparel, which likely explains decreasing complaints about these apparel items. These findings raise concerns regarding health impacts and other benefits associated with physical activity or exercise among both elderly individuals and PLWD.
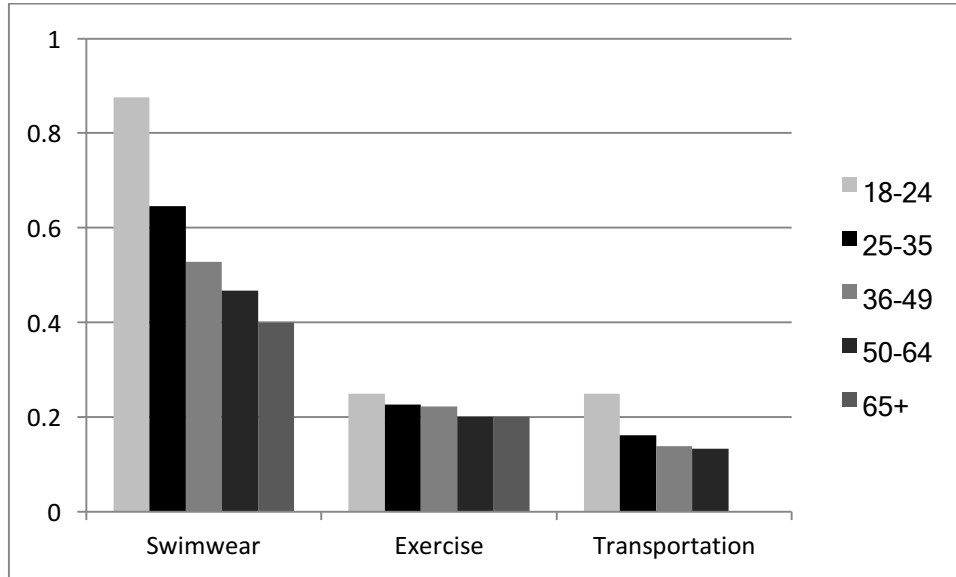
Figure 2. Proportion of Age Group Reporting Apparel-Related Concerns to Indicated Questions

Important Concerns for Intermediate Age Groups

Rather than a relatively straightforward increase in difficulty with age, other responses demonstrate more problems associated with activities and concerns most likely to be undertaken by members of intermediate age groups. As indicated by Figure 3, these groups tend to be more likely than members of the youngest adult age class (e.g. university students) or the oldest age class (e.g. post-retirement) to "sometimes" or "routinely" experience apparel-related issues that raise concerns about employment or education barriers and romantic relationships, or cause them embarrassment or to miss out on something. Some of these responses therefore may reflect the "stage of life" individuals are in, such as more employment-related concerns for adults in prime or middle adulthood. Overall minimal barriers reported in education-related activities, however, could reflect the resources available to schools that are legally required to meet the needs of individuals with disabilities.
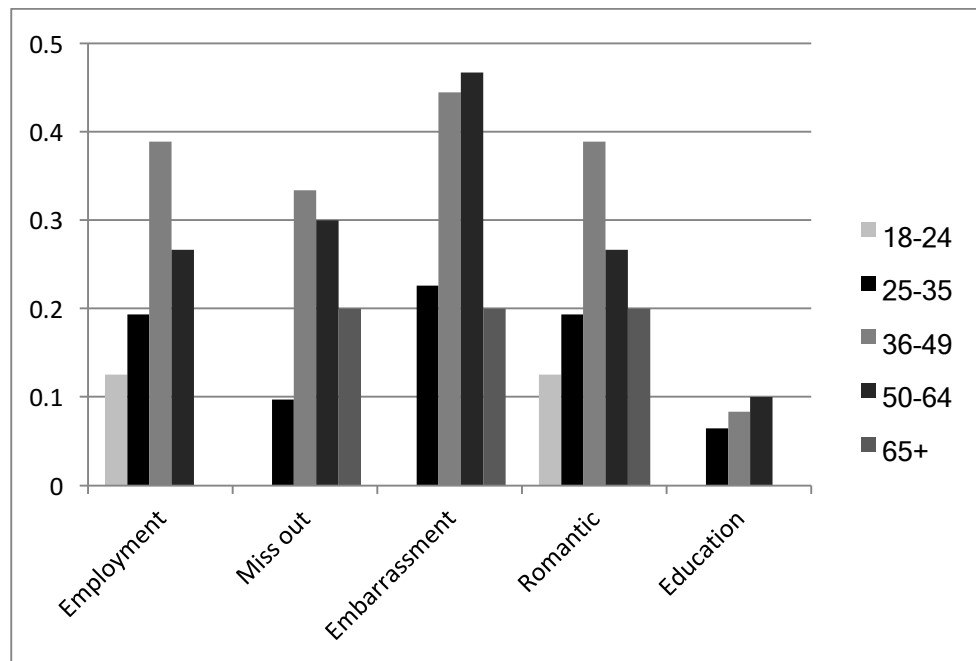
Figure 3. Proportion of Age Group Reporting "Sometimes" or "Routinely" to Indicated Questions

Discussion

Two broad results emerged from a variety of questions addressing apparel-related barriers to everyday life. These results included (1) difficulties finding or purchasing appropriate clothing and some apparel-related barriers to participation were more frequently reported by respondents in older age groups and (2) the increase in complications were not simply directly associated with aging. Rather, particular concerns are reported to be more relevant to younger and intermediate age groups, likely due to the shifting priorities of older adults as well as the lack of desirable clothing designed and marketed toward older consumers especially.

An interesting and unexpected trend associated with the first theme is that, while the proportion of respondents indicating particular barriers varied by age, the nature of complaints often was similar across all age groups. For example, respondents often mentioned difficulty finding suitable shoes, navigating fitting rooms, or finding age-appropriate clothing. While it is important to remember that the underlying needs (such as what qualifies as age-appropriate for different groups) may vary, the general themes were often consistent. Further, participants noted that these difficulties led to decreased social engagement, which could contribute to additional health or quality of life issues. This is consistent with the existing research on participation and disability (Jaeger, Röjvik, and Berglund 2015; Mikula et al. 2015). Thus, these findings support the argument that clothing belongs among the external or human environmental factors to consider when assessing the level of impairment or functioning in individuals according to ICF methods. Further, these findings contribute to anthropological research about the nuances of independence among PLWD and/or aging individuals by documenting the existence of and attitude about barriers to independence.

The second important result to take from this survey is the recognition that age-related changes in clothing needs and the disablement process cannot simply be assumed as a linear progression in difficulty with older age. Age cohorts reflected common culturally and generationally ingrained life course expectations (Becker 1994). For example, the age groups used in this study likely correspond with early adulthood or college-aged adults, intermediate groups whose members might be more likely to have stable employment or family responsibilities, and retirement-age and older individuals. Specific needs and activities require or even demand participation in professional or personal arenas that cause apparel-related challenges for younger age groups but may be less of a consideration for older groups, such as employment obligations or pursuing romantic relationships. However, the "causal" direction in the relationship between age and participation in these types of activities, and how clothing challenges intersect that relationship, is unclear. For example, do older adults actually experience less difficulty with certain clothing-related barriers to social participation, as reported in many of the related survey questions? Do they have fewer social or professional obligations, or feel less social pressure to dress in a specific manner? Perhaps the clothing on offer for older consumers with disabilities is less desirable and presents no added benefit or improvement over items they already own, as suggested by Twigg (2013).

One question in particular (the "Participate" question) suggested that members of older age groups are more likely to decline opportunities for activities, events and experiences and so may not even attempt to search for suitable clothing, explaining the low responses to other questions related to social engagement. Thus, one avenue of further research is to expand these questions to address *why* respondents reported particular difficulties, rather than ask about the presence or severity of the difficulties as was done in this stage. Further research will be required to address these questions more comprehensively.

Further, several participants made a point to specify their issues with finding clothing were not necessarily related to disability but characterized the difficulties instead as a matter of personal style. As suggested by previous anthropological research, clothing and how it is used to express identity, can be influenced by multiple factors including historical context, personal preferences and even emotional and practical concerns of caretakers. Future research will be required to tease apart how stylistic choices are made independently or in conjunction with needs related to impairment or age.

In addition to these contextual issues, an important limitation of this study is the overall sample size, as well as the relative sample size of different groups. The oldest and youngest age categories in particular were under-represented among respondents. Results, therefore, are preliminary and represent possible trends that need to be explored further. Nonetheless, collapsing the age groups into fewer, larger sets typically still demonstrate similar patterns.

Conclusion

A variety of factors are likely to contribute to the number, as well as the age profile, of people classified as living with disabilities now and in the future, including changes in diagnostic criteria, injuries suffered by military personnel, continued modifications of the built environment in accordance with the Americans with Disabilities Act, changes in services associated with health care reform, and an aging population. Therefore, it is important for clinicians, occupational therapists, clothing designers and manufacturers, researchers and policymakers to be aware of the varied ways that clothing-related issues can affect both the functioning and

quality of life for PLWD of all ages. Importantly, although the reported severity and frequency of these issues vary by age, results from this survey study demonstrate that participants raise repeated and common concerns with clothing availability and design and how clothing influences social engagement. These results suggest that actions to alleviate barriers both within and across different age groups may be reasonably accomplished. In particular, disregarding specific disability categories and instead focusing on how clothing items more generally affect structure, functioning and social participation – an approach advocated by the ICF – provides a productive framework for addressing apparel-related concerns.

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