

WOMEN OSTOMATES: IDENTIFYING APPAREL DESIRES AND BEYOND

A Thesis

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by

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ABSTRACT

The aim of this exploratory research is to better understand the apparel needs and desires of perimenopausal women who wear an ostomy bag. The word ostomy comes from ancient Greek which means an opening or mouth (Kilic, Taycan and Belli, 2007, p.1). The United Ostomy Association of America defines ostomy as, “A change in the way urine or stool exits the body as a result of a surgical procedure. Bodily waste is rerouted from its usual path because of malfunctioning parts of the urinary or digestive system.” (What is an Ostomy, n.d.). Having an ostomy may prevent some women from comfortably wearing clothing considered easy or simple to wear by women without an ostomy. The purpose of this research was to identify the apparel needs and desires of perimenopausal women who have an ostomy and wear an ostomy bag. This research explored women’s relationships to the clothing they currently wear, the limitations and challenges they face, the adaptations they had made, and the benefits and drawbacks of current apparel modifications.

BIOGRAPHICAL SKETCH

Jessica Guadalupe Estrada was born in Houston, Texas on May 28, 1995, daughter of immigrant parents Mr. and Mrs. Estrada. She was the first in her family to receive a high school diploma from Magnolia West High School, Magnolia, Texas in 2013, making her a first-generation student. She then enrolled in the Department of Family and Consumer Sciences at Sam Houston State University in Huntsville, Texas. She became a member of the Ronald E. McNair Scholar Program in September, 2014, and began researching apparel modifications for health condition purposes. During her sophomore year and upon graduating she served as a teaching assistant for the introductory sewing courses. Jessica graduated from Sam Houston State University on May of 2017, with a Bachelor's of Art degree in Fashion Merchandising, Spanish and minor in General Business.

In August, 2017, Jessica entered the Graduate School at Cornell University, Department of Fiber Science and Apparel Design. As a graduate student she served as a teaching assistant for the activewear and product development course. At Cornell University she continued researching Her research work was completed in May of 2019.

I dedicate this thesis to my family for their unconditional support, countless prayers,
and reminding me of where I come from and where I can go.

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Introduction

Feeling comfortable in one's clothing allows for movability, expression of identity, and feeling good. Although every woman has her own comfort zone, not all clothing accommodates unique needs. Certain health conditions may prevent some women from wearing clothing that is considered easy or simple to wear by women who are able-bodied. Wearing an ostomy bag, for example, is one kind of health condition that affects women's ability to wear certain types of clothing. The aim of this exploratory research is to better understand the apparel needs and desires of perimenopausal women who wear an ostomy bag. The purpose of this research was to explore women's relationships to the clothing they currently wear, the limitations and challenges they face, the adaptations they have made, and the benefits and drawbacks of current apparel modifications.

It may be difficult for certain consumers to shop and find clothing because, retail facilities do not always provide sufficient services and products that would meet the needs of consumers with particular health conditions (Curteza, Cretu, Macovei, & Poboroniuc, 2014). Retail outlets and brands also do not tend to provide information to consumers about possibilities for do-it-yourself (DIY) apparel modifications. This dearth of apparel options prompted the following questions: For women who wear an ostomy bag, what are the most important apparel improvements and modifications needed? What type of fabrics would be most ideal? Are certain brands or branded clothing preferred?

Literature Review

Originating from ancient Greek, ostomy means an opening or mouth (Kilic, Taycan & Belli, 2007, p.1). The United Ostomy Association of America, Inc. defined ostomy as, “A change in the way urine or stool exits the body as a result of a surgical procedure. Bodily waste is rerouted from its usual path because of malfunctioning parts of the urinary or digestive system. An ostomy can be temporary or permanent” (What is an Ostomy, n.d.). There are three common types of ostomies; colostomy, ileostomy, and urostomy. A colostomy is created when the colon or rectum is removed due to disease or damage in the colon area. An ileostomy is performed when a disease of injured colon cannot be no longer be treated with medication. Lastly, a urostomy is performed due to the bladder not functioning and/or must be removed.

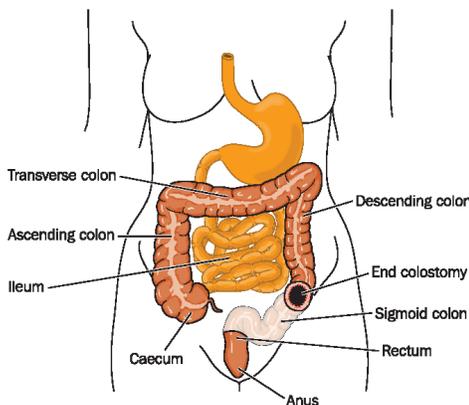


Figure 1. Colostomy

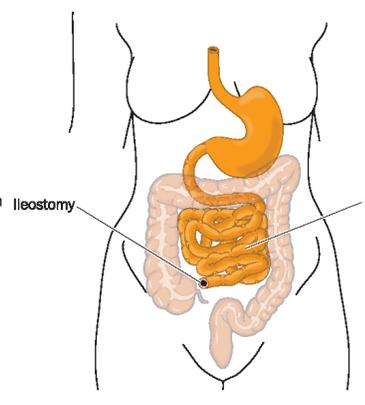


Figure 2. Ileostomy

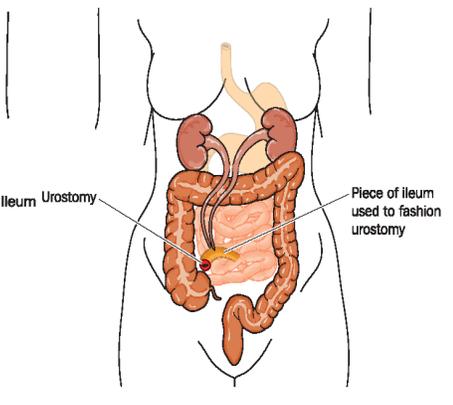


Figure 3. Urostomy

All three images. Source: Shutterstock (2019)

This study focused on apparel needs of women who had an ostomy and wore an ostomy bag. The need for an ostomy surgery depends on each individual's condition such as: rectal cancer, Crohn's disease, and diverticulitis, to name a few. These kinds of surgery procedures are done between the colon, ileum or bladder and

the abdominal wall so that urine, mucus or other bodily waste may be discharged (Jansen et al., 2015, p. 1690). Ostomy patients often suffer from symptoms including leakage, skin irritation, parastomal hernia, fluid and electrolyte imbalance, intestinal obstruction or stoma prolapse, which may impair their quality of life (Jansen et al., 2015, p. 1690). Leakage may cause, skin irritation, other impediments to daily life, and permeant staining on clothing. According to Zonderman and Vender (2000), most patients try to find a baseline for the disruption that their health condition causes and seek medical advice when there are changes from the baseline (Zonderman & Vender, 2000, p. 37).

Apparel for Medical Needs

Design of functional garments for individuals with particular medical conditions has often been limited to research and development conducted by industry rather than academia. As a result, functional garments are expensive and not always responsive to the needs of consumers. Many women who wear an ostomy bag lived under the permanent stress of having no choice but to acquire clothes from regular stores (Curteza, Cretu, Macovei, & Poboroniuc, 2014, p.282).

Textiles and apparel provide protection to people; however, those with certain health conditions may rely more upon different functional aspects of garments. As scholars Curteza et al., (2014) have argued, “Clothing for those with special needs form a class of functional clothing that is developed to improve the quality of life of disabled persons (and not only) whose body shape, size, mobility and dexterity are

significantly different from that of those without adverse health condition” (Curteza et al., 2014, p. 282). Functional apparel can play a life-changing role in somebody’s everyday life experience. For example, Jansen et al., (2015) researched ostomy patients with and without cancer. The purpose of the study was to compare each participant’s quality of life (QoL) to understand the needs of patients. Information on potential differences in QoL between ostomy patients with different conditions may provide insight into groups of ostomy patients in need of additional supportive care and into opportunities for clinical care enhancement (Jansen et al., 2015, p. 1690). My research focuses on how modified apparel can improve a participant’s quality of life and possibly create improved designs.

Apparel Modification for Women

It is important for women with an ostomy bag to feel comfortable and independent in their clothing. This research focuses on the experiences of women who wear an ostomy bags: What do they struggle with? Do they modify clothing? What functional garment needs did they have? How might current or future limitations affect their comfort level and self-esteem? Not only is clothing a form of protection, it is an important mode of self and cultural-expression (Kaiser 2012, p.12).

Roach and Eicher et al., (1973) pointed out how clothing is ambiguous and dynamic because it is linked to the body, physiological, as well as social and cultural environments (p.50-51). The clothing one chooses to purchase and wear is intricately linked to aspects of one’s individual and social identity (Change et al., 2014, p. 36).

Every person, whether they acknowledge it or not, expresses themselves through the clothing they choose to wear.

The relationship between design, science, and society is critical: how does a designer make something that retains functionality across multiple uses and yet could be aesthetically desirable? Functional apparel scholars Watkins and Dunne (2015) have argued, “The design of functional clothing ties together science and art. The evidence-based methods and processes of engineering are combined with the creative, intuitive methods and processes of art and fashion. Most important, because all functional clothing was worn by humans, the human user was at the very center of all functional clothing design activities” (p. 1). Like so, the research study conducted was designed to primarily focus on women who participated, their lives, and then followed their clothing needs and desires. This was important to understand for consumers and producers. Clothing that benefits an individual with physical limitations is known as adaptive clothing, appropriating clothing, and modified garments.

The health caregiving websites, Disabled World, identify adaptive clothing as easy to wear by elderly or those with certain health conditions that might limit their independence when putting or taking off clothing. Having adaptive clothing with Velcro, elastic, buttons, or zippers allows individuals maintain control over their wardrobe (Disabled World, 2019). Appropriating clothing in this case refers to clothing being taken from its main purpose and used to fulfill another purpose for the individual who is redirecting its use. Modified garments are those that are taken from

its original state and altered to better fit the individual who is to wear the clothing. All four of these clothing classifications

Daily Life and Challenges: Body Image, Self-Esteem and Sexuality

Previous research by Carlsson, Berlund, & Nordgren, 2001 has indicated an array of challenges for women who wear an ostomy bag: a life marred by leakage, peristomal skin problems, odor, decreased working capacity, insecurity, less time to participate in leisure activities, and problems with clothing and sexuality (p. 96-97). According to Carlsson et al., (2001) individuals are able to adapt to an ostomy or conditions such as short bowel syndrome; however, life is altered (pg. 96). Research participants expressed troubles with clothing; however, no further information was taken to understand this issue or how to accommodate the patients. Honkala & Bertero, (2009) found that women did not want to be in situations which would or could expose their ostomy. (p.21). For instance, tight-fitting clothing was something many women eliminated from their wardrobe to prevent the ostomy bag from protruding, changing their female curves and womanliness (p.21). In addition to the ostomy protruding, the position of the ostomy impacted comfort and how women dressed; therefore, they often chose to, dress in baggy clothing (p. 21). This allowed their bodies to minimize any type of exposure to the ostomy (Honkala & Bertero, 2009, p. 21). Participants were asked to identify things they did to prevent leakage or discomfort. Several said they were able to do things they did prior to an ostomy but with more self-consciousness or in different order (Carlsson et al., 2001, p. 98). For example, something simple like going to dinner and followed by the movies for most

had changed, instead they preferred to watch the movie and then go to dinner. This was done to prevent getting up to empty out the bag or leakage (Carlsson et al., 2001, p.98). Other experiences that hinder women and cause discomfort due to fear of leakage or odor are social interactions and activities, traveling, shopping and other public spaces which many lack convenience (Honkala & Bertero, 2009, p. 20). An aspect of life that was difficult to sustain for several patients was their job. All had communicated with their employer on their condition and limitations (Carlsson et al., 2001, p. 101). Respect was not lost and patients did not report feeling neglected; however, many had a difficult time staying on top of their work like other colleagues and the frustration caused a few to think about quitting their job (Carlsson et al., 2001, p. 101).

Body Image & Self Esteem

Researchers have found that reduced self-esteem tends to occur when a stoma is created (Sprunk & Alteneider, 2000, p. 86). One can overcome low self-esteem and live life as normally as possible by accepting the ostomy and not letting it become a handicap (Honkala & Bertero, 2009, p. 21). Many women who have an ostomy do live better lives than before the ostomy surgery. Finding new ways of adapting to their new daily lives was important because for many the ostomy saved their lives (Honkala & Bertero, 209, p. 21). According to Honkala & Bertero et al., (2009) women with ostomies experienced lower value as women, since they felt in comparison with other 'healthy' women that they look different. As a cultural aspect, the women felt that

bodily waste was something that should be hidden. Women should be clean and attractive, but their ostomy made them feel insecure and uncomfortable (p. 21). Although many women might still be insecure of themselves due to the ostomy, in recent years social media platforms such as Instagram have created a gateway for women to empower other women with similar conditions. Instagram pages such as *Ostomy Inspiration* are ideal platforms for women with an ostomy to build, “a community where women can find inspiration” (Ostomy Inspiration Instagram Page, n.d.) This page showcases women of all ages with an ostomy who share their story with thousands of followers. Beyond supporting women, articles, documentaries, stats and more is shared to empower this community. Another social media support group, *Girls with Guts* through Facebook is run by women for women. Just as Honkala & Bertero found back in 2009, women are no longer hiding their ostomy nor are they afraid to share awareness.

Sexuality

It is important to know that people with an ostomy are fully human, and therefore also have needs related to the expression of sexuality (Sprunk & Altener, 2000, p. 85). Sexuality can be affected when undergoing body change caused by an ostomy. How does this impact an individual’s sexuality? Each woman experiences different procedure’s which can result in a temporary or permanent use of ostomy bag. Pelvic operation, rectum removal ostomy surgery can cause a lot of damage and change to the female body, lack of lubrication or causing shifting of organs (Sprunk &

Altener, 2000, p. 85). The physiological impact on female sexuality may cause dyspareunia or painful intercourse. Many participants explain that it has also decreased their sexual desire (Kilic, Taycan, & Belli, 2007, p. 6).

To better understand the effects caused by an ostomy on patients who wear a colostomy, ileostomy, or urostomy bag, Kilic et al., (2007) measured responses by men and women. They measured six different scales on married women: (1) Sociodemographic Data; (2) Golombok-Rust Inventory of Sexual Satisfaction; (3) Body Image Scale; (4) Rosenberg Self-Esteem Scale; (5) Dyadic Adjustment Scale; (6) SCID-NP for identification of DSM-III R axis I disorders (Kilic et al., 2007, p. 3-4). According to Kilic et al., (2007) a major finding was that women had a higher sexual dysfunction and were disturbed by their body image more than men (p. 5). Some of the women in Carlsson's et al., (2001) study expressed how the ostomy bag had altered their way of thinking about themselves and now felt unattractive, negatively affecting their sex life (p. 100). Another factor that may cause reduction of sexuality among women is the reaction their partner might have towards the ostomy (Sprunk & Altener., 2000, p. 86). Issues like leakage, noise, odor, etc., could be some of the primary reasons of embarrassments during intimacy. Women who do not have an established partner find it concerning to be intimate with someone that might not understand their health condition (Sprunk & Altener., 2000, p. 86). These factors may cause individuals to feel a lack of acceptance or fear rejection with potential partners (Sprunk & Altener., 2000, p. 86). Trying to conceive can be a concern for women with ostomies between 20-30 years of age. Concerns about the

genetic inheritability of their medical condition are among the most pressing concerns for those choosing to start a family (Zonderman & Vender, 2000, p. 53). Although fertility is not affected by the disease there are still possibilities of fever, anemia or infections to occur more often (Zonderman & Vender, 2000, p. 53). According to Zonderman & Vender, (2000) when a parent has an illness, which causes an ostomy the healthier parent is seen as the one to sustain the family. Their children, if any, tended to be closer to the healthy parent due to him/her being more accessible or active and is not limited to be involved in their daily lives (Zonderman & Vender, 2000, p. 79).

Many of the studies found regarding ostomies primarily focused on the health condition and the positive or negative effects caused to the participants. Most of the topics covered included mobility, body and mind, or diet to name a few. This research adds to the existing literature by examining the apparel needs and desires of women who have an ostomy bag.

Methods

This study utilized quantitative and qualitative research methods, including surveys and in-depth interviews, to understand women's perspectives about clothing while wearing an ostomy bag. This study was divided into two parts: Phase One included a questionnaire and Phase Two included open-ended, in-depth interviews. For Phase One a snowball sample was used, which was possible through social media recruitment. Several Facebook support groups like Girls with Guts, United Ostomy Associations of America (UOAA), Pittsburgh Ostomy Society, Ostomy Association of

Southern New Jersey (OASHJ) and Ostomy Inspiration via Instagram shared the study flyer and their members liked, commented, and also shared the flyer. The questionnaire included 23 questions including multiple choice (6), Likert scale (4), single selection (10), and short response (3). All responses were kept confidential; however, if the participant agreed, her initials and email address were provided for a follow-up interview.

A total of three follow-up in-depth interviews were conducted and lasted approximately 45 minutes each. At the end of the survey participants were asked if they wanted to partake in this phase, if so, they would provide first and last name initials plus their email address. In-person interviews provided greater understanding and insight into individual needs and the differences between each woman's experiences. The combination of survey responses and in-depth interviews gave several different perspectives on lifestyle, needs and wants regarding garments, and how the severity of various health conditions may affect clothing choices. Each interviewee was listed as Participant A, Participant B, and Participant C.

The survey was designed to acquire as much detailed information as possible in order to provide clear understanding of what each individual woman had experienced and desired, and if how she had voiced her opinion on the matter. A thematic analysis of questionnaire responses revealed a number of patterns across women's experiences. Women were able to partake in the survey either via a link or QR code which could be viewed on a computer or smart phone. Prior to filling out the survey each participant had to read consent form and grant consent by pressing "I

agree to participant in this study” in order to continue. In all, 199 responses were submitted of which only 149 were completed. For the most part, all questions were answered; however, respondents did have right to leave questions unanswered if preferred. The questions amounted in an array of demographics, health conditions, desires for modification, and price point, which can be found in Appendix 4 with further detail. All data collected from the survey was analyzed through JMP Pro a statistical software. There were no explicit questions or measures regarding self-esteem or body image since the study primarily focused on understanding the needs and wants of women for their clothing. But it would have been interesting to see how self-esteem was related to these preferences.

Results

A total of 149 women participated in the survey. Ages ranged from 18-60+.

The distribution is shown in Table 1.

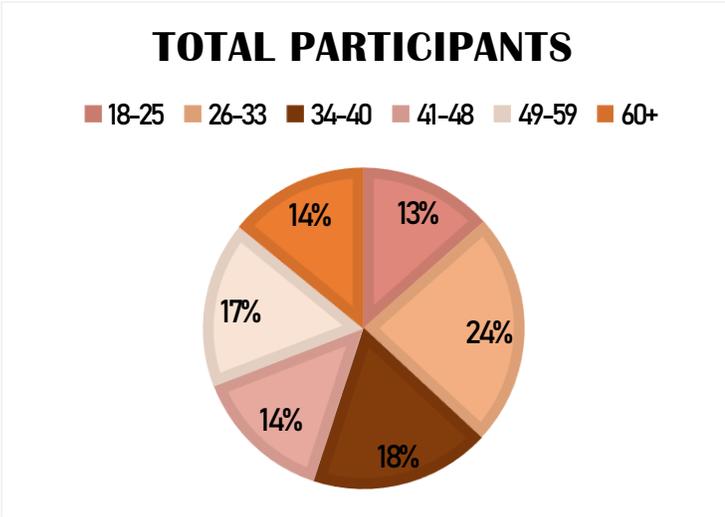


Table 1. This is the total of all 149 women’s age range who participated in this study.

The majority of women who participated were white (90%) followed by Hispanic/Latino (3%), black (2%), Middle Eastern (1%), and other (3%). Due to a limited number of minority participants this study does not take into account differences among ethnic/ racial groups.

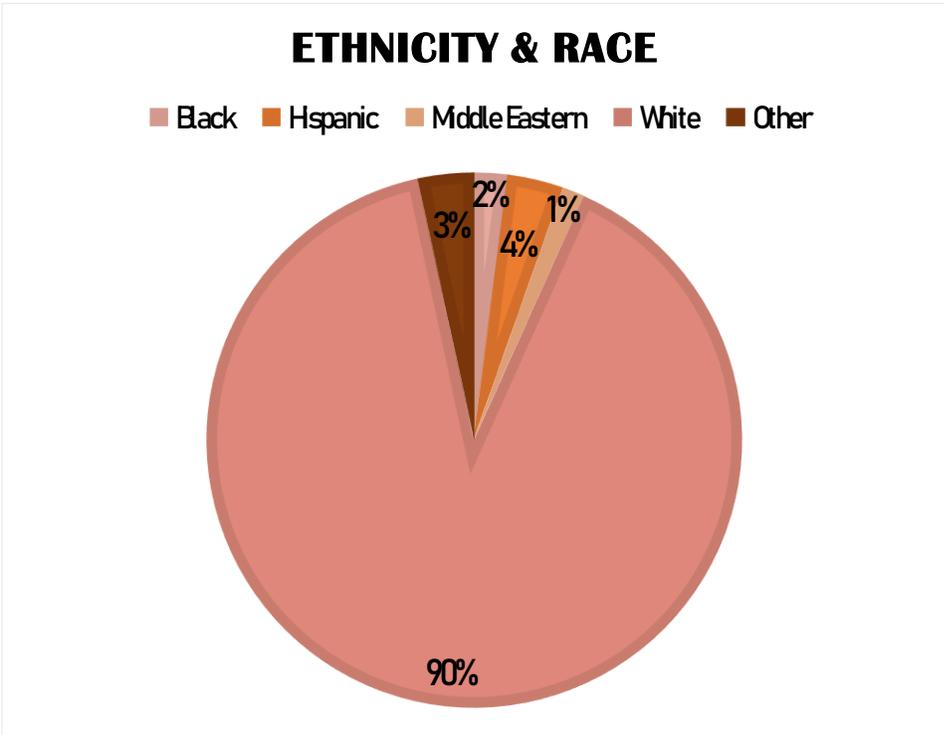


Table 2. *Ethnicity & Race of total participants.*

All three in-depth interviewees were white women between the ages of 28-36. This provided a broader perspective on life style, needs and wants of most participants within the same age range. Information about residence was also part of the demographic questions and 18% (N=27) lived in rural areas, 55% (N=82) lived in suburban areas, and 27% (N=40) lived in urban areas. An overview of where respondents reside was beneficial mainly to comprehending accessibility to resources such as modified garments.

Most women had at least one occupation. The options for occupations were very broad in order to get an overview of their daily lives and were listed as employment statuses. They were able to select several options if applicable. Participants' occupations/ employment statuses reflected a variety of differences which might influence their wardrobe. Parenting was recognized as an occupation within this study due to the daily impact and responsibility required. This was done to identify the differences among categories such as work full-time (FT) only, work FT & parent, work part-time (PT) only, and work PT & parent. This information was recorded to broadly understand if there was an impact on their occupations due to the clothing, they wore alongside their health condition.

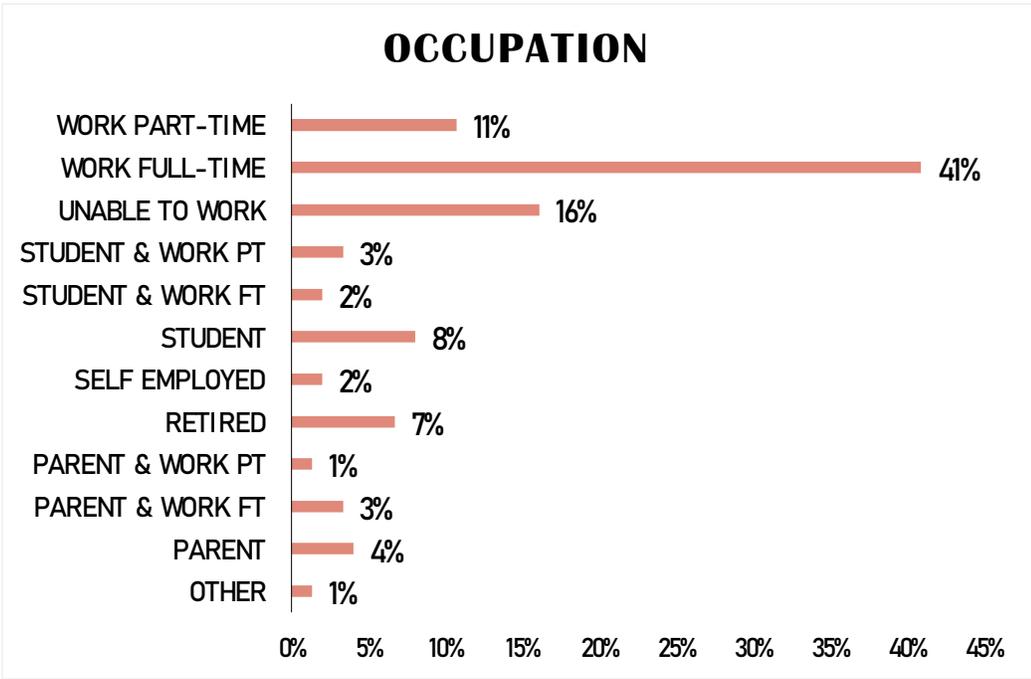


Table 3. Total occupations of each participants.

During the in-depth interviews more detail was provided and understood. for information was Participant B, a health administrator and Participant C, a clinical social worker required to wear business casual attire. The top choice of clothing for Participant A was high waisted pencil skirts due to comfort and because the waistline avoided her ostomy. Participant C accommodated her professional clothing to her ostomy by wearing maternity slacks, undershirts and loose dress shirts. She wore maternity clothing due to the elastic at the waistline that allowed her to move more freely and feel comfortable. The tight undershirt helped support and maintain the ostomy bag in place. While wearing loose shirts allowed her to conceal the bag from onlookers and also prevented her from feeling self-conscious. Additional questions regarding whether, and if so, how their ostomy had an impact on their occupation would have been beneficial in order to present ideas on how to overcome any challenges through clothing.

An ostomy can be caused by many different health conditions and 17 were reported in the questionnaire. The two most common health conditions were Crohn's disease 46% (N=69) and colitis 25% (N=37). According to the United Ostomy Association of America, Inc. website there are approximately 725,000 to 1 million people in the United States with an ostomy (Living with an Ostomy n.d.). This estimate was not broken down into gender. In a previous study some women also indicated having several of these health conditions at different stages of their lives, but only provided their current health condition for this question. Not all health conditions could be assessed in relation with one another due to the severity of each individual's

case. In an upcoming subcategory more information is presented regarding the amount of years each woman has had an ostomy due to these conditions and/ or the amount of conditions. Ostomy bags are known to cause skin irritation because of, sensitive skin to the bag, rubbing, and much more depending on the individual. These women were asked if they had ever suffered from skin irritation and 65% said yes, 33% said occasionally, and 2% said never. Participant A was among those who have or constantly suffer from skin issues. This is due to the unevenness of her abdominal area and the medication that caused her skin surrounding her ostomy to become sensitive to most ostomy bags.

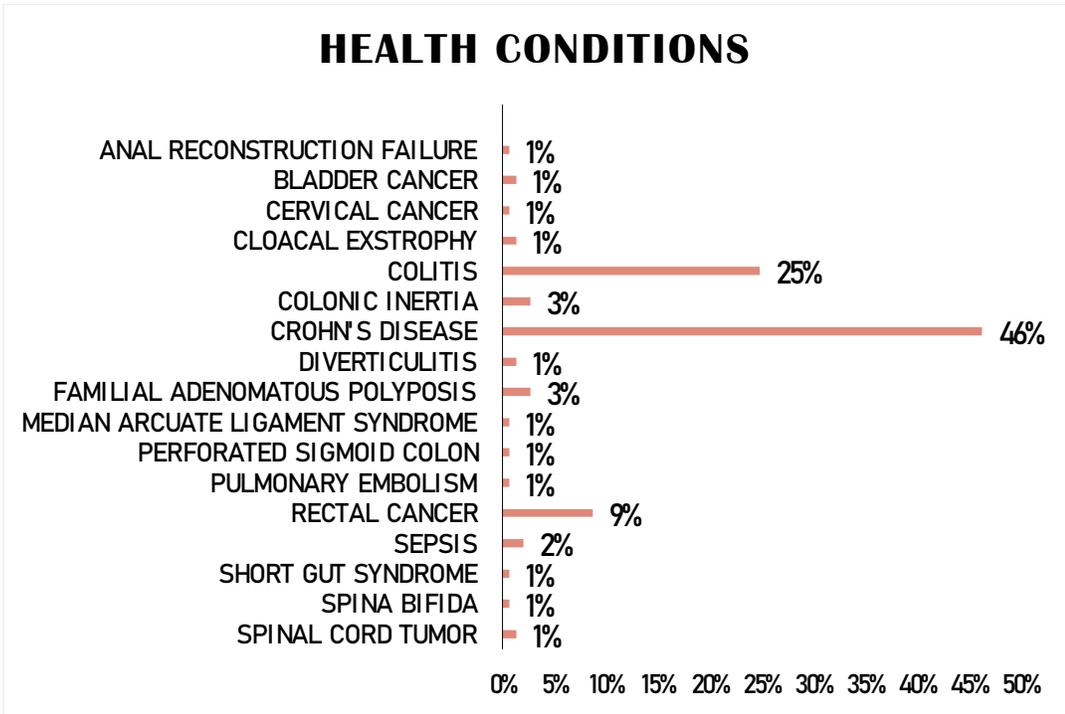


Table 4. Total health conditions which required participants to wear an ostomy bag.

Not only were health conditions important to note, understanding the amount of time that each participant had her ostomy bag was beneficial to record. All three

interviewees had been diagnosed with a chronic disease between the ages of 17-19, this placed them within the 16-20 years range of having an ostomy.



Table 5. Total health conditions which required participants to wear an ostomy bag.

With this information it was easy to identify who had the most recent ostomy and had it the longest. The most recent woman to have an ostomy was just 6 weeks post-operation, whereas on the other side, the woman who had an ostomy longest was for a total of 48 years. Following this it was necessary to comprehend two things; what ‘normal’ clothing did participants find most difficult to wear and how many participants own modified garments.

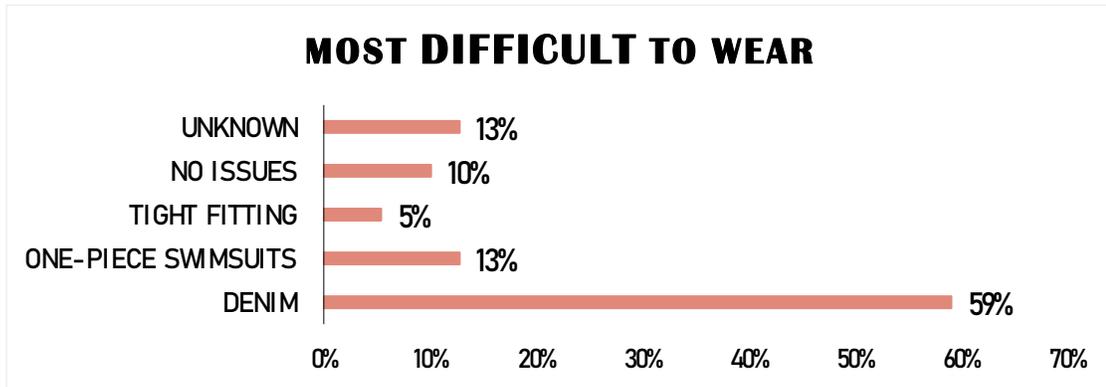


Table 6. *Most difficult to wear.*

The amount of modified garments used by participants was beneficial in regards to understanding how it might impact their daily lives.

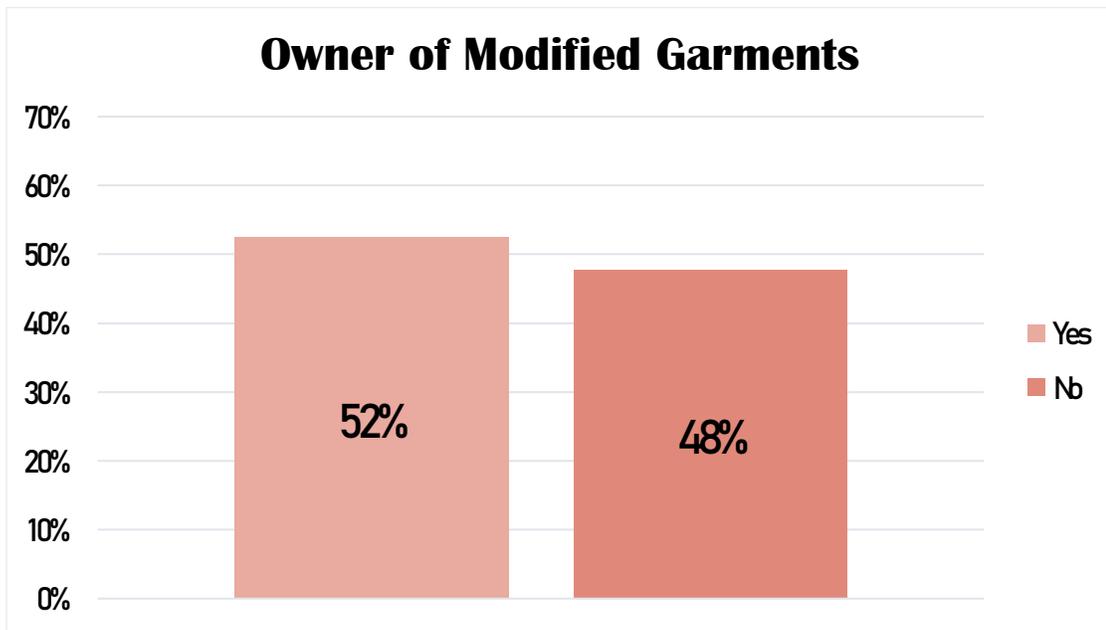


Table 7. *Owner of modified garments.*

From the 52% of women who indicated owning modified garment(s), a total of 43% wore it daily, 31% wore it when needed, 9% only wore it several days per week, 9% only wore it on special occasions, 5% never wore it, and 3% only wore it once a

week. These results provided further information on what participants were or were not wearing. How beneficial was it to each participant. What other needs were not being catered to. This led into the discussion of desires, needs, benefits, price and who participants respond to the clothing they currently wear.

Discussion

Life with an Ostomy

Each woman's unique life experience and context provided a better understanding of her individual issues and how she adjusted or overcame them. Some women provided very detailed information, while others only gave a simple straight to the point response. The terms research participants used when describing "their experience" determined under which thematic category their response would be recorded. The following remarks were taken from the 'life experience' survey question and in-depth interviews. Some positive remarks were provided by survey participants and two of the interviewees:

"I'll take that any day over being in pain!" Participant C said in regards to her ostomy. In 2018 she had the most extensive surgery of her life, which she and support community *Girls with Guts* call it the "Barbie butt surgery" due to the removal of rectum and anus, she now has a permanent ileostomy.

The following participant said, "I had my first ostomy surgery the day after being born. Overall there is no way I could maintain my independence or as

active a lifestyle as I do without my ostomy. Growing up I had some difficulties with self-esteem but my confidence has continued to grow as I get older and realize all the good that comes with having my ostomy.”

Another participant expressed how her ostomy gave her fear but ultimately saved her life, “I was scared and sad at first but it got easier with time. Having an ostomy made me feel better health wise and it saved my life.”

Having brief exposure to the ostomy world, Participant A knew enough to opt for an ostomy rather to continue living with constant pain. She stated, “at that point I did not care, I just wanted to feel better” it did not matter how it would look or how she would have to adjust. Regardless of the lows it also provided this participant a better life. “I have had my ileostomy for 16 years. It has allowed me to experience a greater quality of life and despite some drawbacks, I am grateful to have it.”

Negative responses, were expressed as terrible, painful, difficult, dislike, frustrating, and embarrassing. In spite of providing a better quality of life, several participants including Participant A, expressed the following remarks:

The first few months of wearing an ostomy bag were crucial for Participant A stating how she, “hated it and felt disgusting.” The following three participants expressed distressed due to discomfort and uncertainty of the bag detaching. This participant said, “After the first 3 months, a nightmare that drove me to the edge of suicide, I have largely adapted, but I hate it. I have to be

continually conscious of its needs--dietary, hygienic, and reactive--and to cope with unexpected symptoms of illness--constipation or diarrhea, soreness, bleeding, gas, skin health, and granuloma.” Leakage was one negative complaint among participants, “Colostomy bags have been very frustrating because they don't adhere well to my skin, they leak for reasons no one understands, and I live with the constant uncertainty of bag failure. I'm alive, but I hate this condition.” Another participant stated, “I have trouble with my bag leaking, or not having a right fit. This requires me to wear an ostomy belt that cuts into my waistline because of how tight it needs to be. I also have a tough time finding clothing that covers it as it makes me very self-conscious about it.”

Giving participants the space to express their life and how they felt towards the ostomy, was the first step to understand who these women were. It also allowed them to express and voice those emotions.

Garments to Avoid, to Desire, & to Need

Women tend to avoid particular garments, fabrics, and styles in order to maintain comfort. In the survey, participants were asked which garments they found most difficult to wear, and the answer for more than half of the respondents was denim bottoms. Whether the bottoms were high rise jeans, skinny jeans, or shorts, for 59% (N=88) of women these were the most difficult garment to wear. The only way Participant C is able to wear bottoms close enough to jeans are either maternity jeans

or jeggings. There were different reasons for each: for example, not all denim jeans have spandex or stretch, not all jeans have the same waistline. Participant B recalled the time when low rise jeans were trending, “forget it I tried wearing them but waist hit right on my ostomy.” If the waistline hit right at the ostomy, it was considered uncomfortable and sometimes too tight, which caused pressure on bag and concerns about leakage and skin sensitivity. Women also avoided tight fitting clothing.

Participant A found it hard to feel feminine due to her physique being altered by the pouch with tightfitting clothing and opted to wear baggy clothes. She went on to say, “I want something that fits my body well.” For example, 13% (N=19) specifically mentioned avoiding one-piece swimsuits or leotards. Other participants expressed reasons for avoiding one-pieces was due to the pressure it puts on the bag; on occasion causing the ostomy bag to explode or not being able to access the bag easily. Only 5% (N=8) said they were not able to wear tightfitting clothing. A total of 10% (N=15) had no issue with clothing. The remainder 13% (N=19) were unknown. Overall the most unpleasant clothing item were bottoms without stretch or flexibility around the waist.

Modified Garments in Her Closet, Her Wish List, or Out of Her Reach

Similar to shopping online owning garments specifically for those who wear an ostomy bag can be convenient, easy, or unreliable. Participants who own modified garments were mainly within the age range of 26-33, with overall 52% (N=78) of the entire sample noting that they had purchased modified garments. From this it was important to know how well those modified garments fulfilled its purpose. Out of the

78 women who own some type of modified garments had mixed reviews both positive and negative on how the product(s) supported and concealed their ostomy bag and how much they wore it. Some also listed companies they purchased items from while others sewed their own modified garments. Underwear with a slip to hold the ostomy bag was a piece of clothing that many participants mentioned they own or wore most often. Amongst popular alternatives to modified garments were waist wraps, Spanx or shapewear shorts for everyday use, exercise, or intimacy. For Like Participant C, her ideal modified garment would be, "I'm in need of a good high waisted cute underwear with lace trim and a pocket to place the ostomy bag in."

A total of 12% (N=9) women indicated they mostly bought maternity clothing for better support and comfort. An additional 12% (N=9) of women who owned modified garments had done it themselves by either adding an elastic waist band to her pants, underwear and/or other alterations.

Out of the 48% (N=71) of women who did not own modified garments 11% (N=8) did not think it would function well for them; 49% (N=35) were not aware modified garments existed; 4% (N=3) did not like to wear modified garments due to unflattering appearance; 20% (N=14) found it unnecessary; 10% (N=7) said expensive prices were the main factor; 3% (N=2) found fit issues; and lastly 3% (N=2) were unknown. A participant mentioned fit issues in regard to one size fits all garments which she state, "One size does NOT fit all." The same 71 participants were asked if they would like modified garments for better fit and 32% (N=23) responded most

definitely, 9% (N=6) most definitely not/ most likely not, 24% (N=17) most likely yes, and lastly 35% (N=25) were unsure. Beyond fit, it was necessary to understand what the ideal method to better secure their ostomy bag while maintaining comfort.

Participant A said she daily wears an ostomy belt to support the ostomy bag in place but it cuts circulation around her waist because it is too narrow. Most just wanted whatever would work best 43% (N=64); better belts/ belly bands 17% (N=26); full garments that could hold the bag in place 9% (N=14); undershirts 15% (N=23); vest 2% (N=3); 'other' 11% (N=17) and 1% (N=2) were unknown.

Textile comfort and preference was indicated most wanted breathable textiles, wrinkle-free (WR) and easy-care synthetic (ECS). One participant said, "I wish there were more breathable accessories." In favor of more cotton underwear this participant said, "I would love more underwear with a slot to put the ostomy bag in." Cotton (WR, synthetic blend) was the top choice most women selected 48% (N=72); synthetics (ECS) 6% (N=9); organic cotton 7% (N=11); 'other' 9% (N=14) and 'no preference' 29% (N=43).

Cost of was a factor which prevented some women from purchasing modified garments. First, participants were asked to select the price range they would pay for modified garments. The most popular price range was between \$30 and \$49, this amounted for 67% (N=99) of the women. The price range was not broken down into specific clothing items. The two highest age ranges to select this amount were between

26-40 age range. The second question was whether branded items (a big name brand developed modified garments) would be a factor to pay more for modified garments.

Clothing choices changed when it came to branded modified garments; only 5% (N=8) were very willing to pay more, 26% (N=38) were very unwilling to pay more, 28% (N=41) were somewhat willing to pay more, 10% (N=15) were somewhat unwilling to pay more, and 32% (N=47) said branded garments was not a factor. This showed how some found brands appealing despite a higher price tag. Although an interest in brands was presented more than half of the women indicated that brand items were neither appealing/ nor unappealing to them 52% (N=78); however not far behind was appealing/ somewhat appealing with 42% (N=63). The number one priority for Participant A was best fit but the fact of branded garments did intrigue her.

Conclusion

The knowledge and results this study provided allow for better understanding the experience of women who have an ostomy, and the importance of apparel modification for health condition purposes. Overall, it was determined that about half of the participants wanted to see better comfort fit to their clothing. The other half were fine with their current clothing or did not care for modified clothing. The willingness to pay a higher price for modified clothing was not too appealing to some, one of the interviewees said, "I already spend quite an amount of money on bags... paying more for clothing doesn't seem reasonable." However, when asked about branded items 28% were willing to pay more. Jeans were the least favored clothing

item and 55% of women said they could not or preferred not to wear jeans due to discomfort or tight-fit. When it came to pants and trousers, knits, elastic, and breathable fabrics were the most requested components of a better bottom. Comfort and stability (for the ostomy bag) were the two most important components. Hiding the ostomy bag was not the goal of this study nor was it something participants wanted; however, concerns regarding leakages, odors, or their bag being pressured by clothing were mentioned. Overall, the desire to be able to dress in a way that allowed them to feel comfortable and confident, while expressing their individual and cultural identities, was a priority.

Limitations

Being a woman and conducting research to comprehend the needs and desires of clothing other women have and understanding the female body, was relatable; however, not having an ostomy bag and being outside the community presented limitations. Those limitations were being concerned on the type of questions to ask participants without receiving pushback. Because of this, questions such as self-esteem and intimacy were not asked.

Future Research

The data collected through this study provides the necessary tools and resources to further develop modified garments for better fit, comfort, and the desires women of this study desire. Having the technology of scanners could provide accuracy in the construction of developing custom garments for women who wear an ostomy bag. Other topics of interest to follow this study would be the development of patterns

including the modifications to construct one's own garment. Customized apparel or how to do it yourself (DIY) adaptations could be provided to women who want to make their own modifications. There are many areas of growth through this study and those of modified garments. It is hoped that the results of this exploratory research will be used to develop new garments and new approaches to help solve the clothing problems of women with ostomies.

APPENDIX 1: RECRUITMENT FLYER

Apparel Modifications for Women who wear a **Colostomy, Ileostomy, or Urostomy** Bag

The purpose of this research study is to develop garments for women who wear an external appliance, the result of ostomy surgery. Survey portion of study is anonymous.

Target Participants: **18-year-old - perimenopausal women**



*Scan to take the survey
or go to [https://cornell.qualtrics.com/
jfe/form/SV_cDaNcgNbkoRRNYN](https://cornell.qualtrics.com/jfe/form/SV_cDaNcgNbkoRRNYN)*

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APPENDIX 3: CONSENT FORM

Cornell University
Consent for Participation in Research
Apparel Modifications for Women who Wear a Colostomy, Ileostomy, or
Urostomy Bag

Why am I being asked?

You have been selected to participate in the research because you have been identified as a woman eighteen year of age or old and/or postmenopausal who uses a colostomy, ileostomy, or urostomy bag. This research is being conducted by Ms. Jessica G. Estrada, under the direction of Dr. Denise N. Green, in the Department of Fiber Science and Apparel Design, College of Human Ecology, at Cornell University. Please read this consent form and ask any questions you may have before agreeing to participate in the research.

What is the purpose of this research?

The purpose of this research is to better understand individuals apparel needs and desires who have a chronic disease that requires the use of an colostomy, ileostomy, or urostomy bag. This research asks: (1) What special apparel needs do individuals with colostomy or ileostomy bags have? (2) What modifications or adaptations to existing clothing/apparel is needed to improve comfort and mobility? (3) What new types of functional accessories (i.e., comfort belts, etc.) could be designed to improve comfort and mobility for these individuals?

What procedures are involved?

If you agree to be in this research, we ask that you read and sign this consent form and complete the attached questionnaire. We hope to reach approximately 50 individuals (answer questionnaire) and 5 individuals (be interviewed) through hospitals/clinics, support groups, and/or acquaintances in close proximity to Cornell University (Tompkins County).

What are the potential risks and discomforts?

There is no risk associated with this study beyond what is normally encountered in day-to-day activities.

Are there benefits to taking part in the research?

The potential benefit to this study would be the availability of modified clothing for individuals who use a colostomy, ileostomy, ostomy, or urostomy bag.

Will I be compensated for my participation in this research?

Participants will not be compensated in for participation in this research. If needed to meet at the Human Ecology Building parking will be provided and so will refreshments.

What about privacy and confidentiality?

The only people who will know that you are a research participant are members of the research team. No information about you, or provided by you during the research, will be disclosed to others without your written permission, except if required by law. When the results of the research are published or discussed in conferences, no

information will be included that would reveal your identity. Information gained from this study only will be used in aggregate form.

Physical data/research files will be secured in a locked (Jessica only with key access) drawer located in HEB 263. Ms. Jessica G. Estrada and Dr. Denise N. Green will be the only two to have access to identifying information. Sensitive data will be kept secured in a password locked electronic file.

Please note that email communication is neither private nor secure. Though we are taking precautions to protect your privacy, you should be aware that information sent through e-mail could be read by a third party. **Data may exist on backups and server logs beyond the time frame of this research project. Your confidentiality will be kept to the degree permitted by the technology being used. We cannot guarantee against interception of data sent via the internet by third parties.**

Consent Form

This consent form will be kept by the researcher for five years beyond the end of the study.

Data Sharing

De-identified data from this study may be shared with the research community at large to advance science and health. We will remove or code any personal information that could identify you before files are shared with other researchers to ensure that, by current scientific standards and known methods, no one will be able to identify you from the information we share. Despite these measures, we cannot guarantee anonymity of your personal data.

Taking part is voluntary, can I withdraw or be removed from the study?

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may also refuse to answer any questions you don't want to answer and remain in the study. This will not affect your relationship with the Department of Fiber Science and Apparel Design, College of Human Ecology, or Cornell University. The investigator may withdraw you from this research if circumstances arise which warrant doing so. If the respondent is under 18 years of age, he/she will not be included in this study.

Who should I contact if I have questions?

The main research conducting this study is Ms. Jessica G. Estrada, graduate student at Cornell University.

What are my rights as a research subject?

If you have any questions or concerns regarding your rights as a participant in this study, you may contact the Institutional Review Board (IRB) for Human Participants at 606.255.5138 or access their website at <http://www.irb.cornell.edu>. You may also report your concerns or complains anonymously through Ethicspoint online at www.hotline.cornell.edu or by calling toll free at 1.866.293.3077. Ethicspoint is an independent organization that serves as a liaison between the university and the person bringing the complaint so that anonymity can be ensured.

Agreement to Participate

I have read and understand the above information, and I willingly consent to

participate in this study. I have been given the opportunity to ask questions and my questions have been answered to my satisfaction. I understand that if I should have any questions about my rights as a research subject, I can contact Jessica G. Estrada.

APPENDIX 4: QUESTIONNAIRE

Qualtrics Questionnaire

1. What age range are you in?
 - 18-25
 - 26-33
 - 34-40
 - 41-48
 - 49-59
 - 60+
2. What is your ethnicity?
 - White
 - Hispanic, Latino, or Spanish origin
 - Black or African American
 - Asian
 - American Indian or Alaska Native
 - Middle Eastern or North African
 - Native Hawaiian or Other Pacific Islander
 - Other or mixed ethnic origin
3. How would you describe where you live?
 - Urban
 - Suburban
 - Rural
 - Other
4. What is your occupation?
 - Student
 - Parent
 - Work full-time
 - Work part-time
 - Unable to work
 - Other
5. How active would you consider yourself?
 - I exercise daily
 - I exercise once in a while
 - I do the minimum
 - I do not have time/like to exercise
 - Other
6. What medical condition requires you to use a colostomy, ileostomy, or urostomy bag?
 - Crohn's
 - Colitis

- Bowel cancer
 - Diverticulitis
 - Other
7. How long have you used a colostomy, ileostomy, or urostomy bag? What is your experience?
-
8. Have you ever suffered of skin irritation caused by a colostomy, ileostomy, or urostomy bag??
- Yes
 - Occasionally
 - Never
9. What garment(s) do you find most difficult to wear?
- High rise jeans
 - Skinny jeans
 - Denim shorts/skirts
 - Dresses
 - Rompers
 - One piece swimwear
 - Shirts
 - Other
10. What type of garment(s) are you not able to wear?
- High rise jeans
 - Skinny jeans
 - Denim shorts/skirts
 - Dresses
 - Rompers
 - One piece swimwear
 - Shirts
 - Other
11. If you do or have own modified garments/ accessories, how often do/did you wear it?
- Daily
 - 4-6 days a week
 - Special occasions
 - When needed
 - Never
12. Do/have you own any modified garment(s) and/or accessories?
- Yes
 - No

13. If you do/have what is it and how does it fulfill its purpose?

14. Do you have any criticisms of the garment(s)/accessories or hopes for future design(s)?

15. If you do not own modified garment(s)/ accessories, why not?

- I was not aware modified garments existed
- I do not think it would function well for me
- I do not like to wear them because they don't have a nice appearance
- They seem uncomfortable
- Other

16. If you do not, would you like to have modified garments for better fit?

- Most definitely
- Most likely yes
- Unsure
- Most likely not
- Most definitely not

17. Would clothing modifications to accommodate use of an colostomy, ileostomy, or urostomy bag be helpful?

- Very helpful
- Somewhat helpful
- Neither helpful/ nor unhelpful
- Somewhat unhelpful
- Very unhelpful

18. What would be the preferred method for securing the colostomy, ileostomy, or urostomy bag?

- Vest
- Belt
- Undershirt
- Full garment that holds the bag in place
- Whatever works best
- Other

19. Which textile choices would you prefer:

- Cotton
- Wrinkle free cotton
- Organic cotton
- Easy care synthetic (for example, polyester)

- No preference
 - Other
20. Would a branded product be appealing to you as a consumer of clothing modified for use with a colostomy, ileostomy, or urostomy bag?
- Appealing
 - Somewhat appealing
 - Neither appealing/ nor unappealing
 - Somewhat unappealing
 - Unappealing
21. Would you be willing to pay more for branded items?
- Very willing to pay more
 - Somewhat willing to pay more
 - Branding of items not a factor
 - Somewhat unwilling to pay more
 - Very unwilling to pay more
22. What price range would you pay for modified garments?
- \$30-\$49
 - \$50-\$69
 - \$70-\$99
 - \$100+
 - No preference
23. Would you prefer new modified garment(s) or modifying currently own garment(s) (yours)?
- New modified garment(s)
 - No preference
 - Modify currently own garment(s)

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- Figure 1. Drawing of an ileostomy (ileum taken out to abdominal wall and a stoma formed) following removal of the large intestine [Online image]. Retrieved April 12, 2019 from <https://www.shutterstock.com/image-vector/drawing-ileostomy-ileum-taken-out-abdominal-104499089>
- Figure 2. Drawing to show the position of a stoma after an end colostomy following the removal of the sigmoid colon [Online image]. Retrieved April 12, 2019 from <https://www.shutterstock.com/image-vector/drawing-show-position-stoma-after-end-104050469>
- Figure 3. Drawing of a typical urostomy, where a small piece of ileum is used to redirect urine to the abdominal wall, following bladder surgery or

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