WE ARE ALL BUILT DIFFERENTLY:

DESIGNING MASS CUSTOMIZATION APPAREL FOR DIALYSIS PATIENTS

USING THE USER-ORIENTED DESIGN PROCESS

by

ELISE V. BROOKS

(Under the Direction of Laura McAndrews)

ABSTRACT

The purpose of this study was to explore why the traditional apparel design process has failed to meet the needs of people living with disabilities, and why current disability design processes have not been successfully implemented into the apparel industry. This study followed Rosenblad-Wallin's (1985) user-oriented design process to discover dialysis patient's wants and needs related to apparel, using in-depth semi-structured interviews, observations, and a design researcher's notebook. This study expanded on the user-oriented design process to alter symbolic values to aesthetic values. Functional and aesthetic values aided with creating designs using mass customization options for men and women. Two prototypes with options were created, which shows that the user-oriented design process and mass customization are viable design processes to implement into industry.

INDEX WORDS: User-Oriented Design Process, Mass Customization, Inclusive Design, Disability Apparel, Dialysis Patients, Disability

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ELISE V. BROOKS

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| Major Professor: | Laura McAndrews |
| Committee: | Lilia Gomez-Lanier |
| | Patricia Hunt-Hurst |

Electronic Version Approved:

Suzanne Barbour
Dean of the Graduate School
The University of Georgia
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# DEDICATION

To my Dad, for unconditionally loving me, always encouraging me to follow my dreams and telling me I can change the world, and inspiring this research study.

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I am also so grateful for all the wonderful volunteers that let me interview them for this study. It was not an easy task to talk about this subject matter, and I am so appreciative they let me into their lives to shed light on their illness and help them have a voice.

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# CHAPTER 1

# INTRODUCTION

Chapter 1 contains the following sections: (a) background of the study, (b) purpose of the study, and (c) significance of the study.

## Background of the Study

Traditionally, the apparel industry designs for the mainstream or traditional consumers, and the industry, in the United States, has continued to overlook the functional and aesthetic needs for underrepresented consumer groups, such as people living with both mental and physical disabilities (Suh, Carroll, & Cassill, 2010). People living with disabilities (PLWD), in the United States, have been discriminated against socially for a great deal of time, but there have been policies implemented to change these societal views especially related with special environments such as, the Americans with Disabilities Act (ADA) in 1990. Even though the ADA has aided in the improvement of public spaces and retail environments, there is still a lack of accessibility in stores and training for employees to have more awareness about PLWD that may enter their stores (Baker, Stephens, & Hill, 2002). Fashion companies have a desire to design products to satisfy their target markets and maintain brand identity with their products, but the same idea can be applied to underrepresented groups that strive to find similar fashionable products in mainstream retail environments (Gwilt, 2014).

Even though there have been positive changes toward bettering the lives of these underrepresented groups of people in the United States, there has yet to be a successful integration of design options for them in the apparel industry (Carroll & Kincade, 2007). At

clothing's most basic level, it is used for comfort and protection and boosting self-esteem (Curteza, Cretu, Macovei, & Poboroniuc, 2014). Apparel has been shown to increase confidence, social skills, and overall life skills, especially for PLWD (Carroll & Kincade, 2007). People are now living longer, so there has been an increase of disabilities with the increase in age; businesses and society will not be able to continue overlooking these underrepresented groups of people (Story, Mueller, & Mace, 1998). There is an underlying assumption that apparel industry companies, designers, and store employees lack knowledge about the experiences, unseen, and unknown problems PLWD have in their daily lives, especially clothing (Baker et al., 2002). This research believes that with the right information and tools, apparel for every ability, and every body can be available at an affordable price to meet apparel needs and wants of all.

In 2010, there were 56.7 (18.7%) million people in the United States diagnosed with some type of disability (Brault & Census, 2012). The ADA defines a person that has a disability as anyone who has a physical or mental impairment or illness that substantially limits a major life activity, such as working, walking, breathing, or learning (Orentlicher, 1996). Defining the term "disability" is not an easy task, and the ADA includes most impairments related to the body and mind, limitations to daily activities, and restricted activities as disabled, even though society or the individual themselves may not view disability in such a manner (Curteza et al., 2014). This definition also includes anyone that is on dialysis or in need of an organ transplant, so for this research the term "people living with disabilities" (PLWD) will be used for the participant group of patients on hemodialysis and peritoneal dialysis (PD). This research includes the participant group of dialysis patients based on personal knowledge about the group, and a lack of research in academia of dialysis patients, especially related to apparel.

Dialysis is a mechanical, medical process that is used on people who have lost more than 85% of their kidney function; dialysis works by removing waste, fluid, and buildup of potassium and bicarbonate in the body (National Kidney Foundation, 2016). Rushing (2010) found that about 550,000 individuals had kidney disease with renal failure in 2010, which is about 10% of the population (as cited by Smith, 2013). According to the National Kidney Foundation (2016), 57.3% of patients were male and 42.7% were women in 2013, and in 2016 more than 661,000 Americans had kidney failure with 468,000 on dialysis. Kidney failure is not always permanent but end stage kidney failure unfortunately is permanent, so patients could be on dialysis for a short or long period of time (National Kidney Foundation, 2016).

Two types of dialysis currently exist: hemodialysis, where a machine that acts as an artificial kidney to cleanse the blood and remove waste, which is accessed through a vascular access site, and peritoneal dialysis, which uses a catheter placed in the abdomen and cleanses the blood inside the body with the use of a machine (National Kidney Foundation, 2016). Peritoneal dialysis can be performed at home and is less strenuous on the body (National Kidney Foundation, 2016). While hemodialysis is usually treated in-clinic or at a hospital, but can also be performed at home with a trained caregiver or nurse (National Kidney Foundation, 2016).

Dialysis patients have a vascular access site or catheter, depending on their treatment and individual factors. Vascular access sites include: a fistula (creation of larger blood vessel by joining an artery and vein under skin), a graft (plastic tube joining an artery and vein), or a catheter (plastic tube located in a large vein in the neck) (National Kidney Foundation, 2016). These access sites are typically located in either the upper/lower arm, upper legs, or neck. Peritoneal dialysis uses a catheter tube that extends from internally to externally and is placed in the lower abdomen area (National Kidney Foundation, 2016). These access site locations may

cause the patient to alter their apparel choices for easier access to their ports, temperature changes inside/outside, and because of staining issues that may arise. Currently, there are a few online adaptive clothing retailers that exist for dialysis and chemotherapy patients, but the clothing may appear: outdated in style, functional with little style, and visually different than mainstream clothing. In addition, clothing options may be more expensive than patients want to pay. The inability to customize apparel related to their needs could also be an issue, since the adaptive apparel available is standardized.

Currently, apparel design processes use traditional, mass production methods to create and manufacture clothing to be sold to mainstream markets. Disability and clothing barrier research tends to focus on the functional aspect of clothing to meet consumer needs, and the disability design processes used in research appear to have had little improvement over the years. The typical design processes used for disability apparel research is adaptive or universal design. The adaptive design process appears to focus more on function and less on aesthetics, while universal design appears to focus on the aesthetic with the ability to create designs that can be used by everyone. Both processes, while feasible solutions, have failed to be successfully implemented into the apparel industry. A design process called, user-oriented design, combines the best of both processes and creates a process that focuses on the user and their functional and aesthetic needs (Rosenblad-Wallin, 1985). This study suggests that mass production may be a barrier to successful implementation of disability apparel into the mainstream apparel industry. This research proposed that along with the user-oriented design process, mass customization may be a viable solution to create affordable products that meet a variety of functional and aesthetic needs by all consumers.

## Purpose of the Study

The purpose of the study was to gain an understanding of why the traditional design process and mass production of apparel had failed to meet the needs of PLWD, and why suggested current disability design solutions have not been successfully implemented into the apparel industry. This research followed the user-oriented design process by Rosenblad-Wallin (1985) to explore dialysis patients' apparel needs and wants, as related to their functional and aesthetic values. These methods were followed because they were suggested in this research to be viable solutions for successful implementation into the fashion industry. The user-oriented design process was reformed from "symbolic values" to "aesthetic values" and included mass customization options to develop design ideas and solutions for dialysis patients that traditional apparel brands could apply. This research also found that the process could be used for the development of clothing for other disabilities. The determination of dialysis patient's use-situation and user-demands that were prioritized into functional and aesthetic values for apparel, was accomplished through in-depth, semi-structured interviews, observation, and a design researcher's notebook.

## Significance of the Study

Exploring clothing needs of dialysis patients, proposing an altered user-oriented design process, and the idea of implementing mass customization into the apparel industry has implications to the fashion industry, society, other disabilities, and academia. First, this research aids in filling the gap of why the traditional design process and current disability design processes are failing to be properly implemented into the apparel industry. The use of mass customization and the expanded user-oriented design process add to research to show a viable solution to create functional, aesthetically pleasing apparel in an inclusive market for everyone.

Second, the fashion industry should note that these underrepresented groups yearn for apparel that meets their wants and needs. It may be fiscally wise for the industry to jump on board early. Society is shifting to a more inclusive style, and the industry will not be able to ignore these groups in the future. This study found that these user-oriented and mass customization design processes can be successful to create apparel for PLWD, and the fashion industry can implement them successfully. People are living longer now and most are going to be elderly and may have disabilities or illnesses that are problematic related to clothing. The fashion industry needs to realize that this is worthwhile market of adequate monetary value to design mainstream apparel for in the future.

Third, this study may be significant not only for dialysis patients, but also for chemotherapy patients (both adults and children) , and anyone that has an external medical device on their body that needs concealment. Mass customization options can also be used for people with mobility issues and difficulties with various clothing closures and trims. Mass customization and user-oriented design can meet any user's needs and wants with the design process proposed in this study. Dialysis patients were the chosen participant group for this study, but it has been shown that many disabilities can be grouped together under major needs (Carroll & Kincade, 2007). This research may be able to fill gaps and combine other disability needs together.

Finally, this study's findings can contribute academia research and textile and fashion design departments. This research can inform future designers that there are other markets than the mainstream one to design apparel for, and that they should not be overlooked or thought of as functional apparel only. This also applies to other markets, such as other disabilities, petite and plus sizes.

# CHAPTER 2

# LITERATURE REVIEW

Chapter 2 contains the following sections: (a) traditional design process and mass production; (b) current design solutions for PLWD; (c) mass customization (d) user-orientated design; (e) research gap and questions.

## Traditional Design Process and Mass Production

The traditional design process for the apparel industry is a part of the basic product development process used in business and engineering (Suh et al., 2010). Companies utilize the product development process to generate potential products, design, and promote products with a focus on responding to consumer needs (Suh et al., 2010; K. T. Ulrich & Eppinger, 2012). The design process is the creative piece that goes into the product development process. Traditionally, apparel is designed for the mainstream market using mass production (Pine, 1993). Mass production and the traditional product development and design process tend to go together, for the apparel industry (Pine, 1993; Suh et al., 2010).

### Traditional Design and Product Development Process Definition

The traditional design process used for the apparel industry focuses on product development issues and improvements for products related to a generalized, main-stream target market (Suh et al., 2010). The traditional design process moves through a linear and sequential process that includes the following main-steps (Kincade, Regan, & Gibson, 2007; Lamb & Kallal, 1992; Pitimaneeyakul, LaBat, & DeLong, 2004; Senanayake & Little, 2001; Suh et al., 2010, p. 4):

1. Generate ideas;
2. Design;
3. Prototype;
4. Evaluate and refine;
5. Production plans

The traditional design process were developed using an engineering process theory that originates with a problem (Suh et al., 2010). This traditional apparel design process follows a continuous loop method that is influenced by the firm size and orientation of fashion, amount of products produced, and a target market focus (Suh et al., 2010). Pitimaneeyakul et al. (2004) emphasized that the main difference with other product development processes and the traditional apparel design process is the timeframe, which is about six to twelve months before the seasonal line arises for the traditional process. Figure 1 is an adapted pictorial representation of the traditional design process used in today's apparel industry.

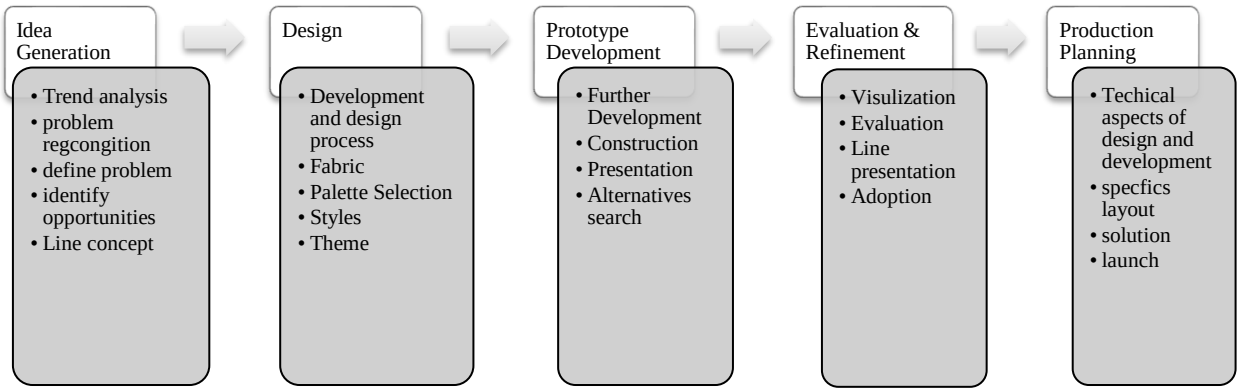


**Figure 1. Current Apparel Industry Traditional Design Process adapted from Suh et al. (2010)**

**Mass Production Definition**

The term mass production was coined by Henry Ford and described as a, "… focus on low costs and low prices, in order to create products for the 'masses' " (Pine, 1993, p. 16). Mass production enhanced manufacturing, with the implementation of assembly lines with specific

machines and workers, to produce large quantities of products quickly and efficiently (Pine, 1993; Senanayake & Little, 2010). This change in manufacturing, in the twentieth century, positioned America at the top of manufacturing and exporting in the world, and it has remained as the leading way to produce large quantities of products (Pine, 1993). The apparel design process usually occurs quickly and allows for change with seasons and trends, with the aid of mass production (Pitimaneeyakul et al., 2004). Often this process can have a negative impact on the companies, because it often leads to an overflow of merchandise and price reductions for apparel retailers (Pitimaneeyakul et al., 2004). Past research suggests that the apparel industry should restructure the design process, instead of focusing on the manufacturing process, to compete more efficiently with other industries and have less waste and overflow (Feitelberg, 2003; Kincade et al., 2007).

**Application**

The traditional design and development process is mainly used for business, engineering, and mainstream products (Suh et al., 2010). Today, mass production is the most commonly used way to manufacture apparel, but this process and its popularity did not occur over night (Davis, 1987; De Raeve, De Smedt, & Bossaer, 2012; Pine, 1993). Previously, craftsmen or artisans, who were specialized in creating specific products, were used for the main production in the United States (Pine, 1993). In the 1800s, machines began to replace craftsmen with machines to produce products at a quicker rate (Pine, 1993). Shortly after the U.S. System of Manufacturing was developed, which used interchangeable parts and U.S. workers to continue to improve the system (Pine, 1993). Henry Ford created his automobile and implemented the assembly line to create his standard product, which has become the standard process for mass production (Pine, 1993).

For the fashion industry, it has been a timely process to reach the point of traditional apparel design and mass production, particularly in the United States. Historically, apparel was designed and created by a 'made-to-measure' system, which meant every garment was created for an individual to fit their exact needs (De Raeve et al., 2012). After the shift in manufacturing, described above, occurred, haute couture and street wear, or ready-to-wear fashion, are the predominate ways apparel is designed today (De Raeve et al., 2012). Haute couture is a business organization for couturiers (designers) to promote, showcase, and sell new, original apparel designs that are one-of-a-kind (Tortora & Eubank, 2010). Ready-to-wear apparel is apparel that is sold as-is in completed condition with standard sizing, usually produced in mass production factories (Tortora & Eubank, 2010). Even though the traditional design process and mass production have been the standard for years, it may not be the best solution to meet every consumer's apparel needs and wants.

**Issues for PLWD**

Apparel that is created through the traditional design process has a focus on business, i.e. financial gains and commercialization, and the problem is a lack of focus on apparel issues and consumer needs. (Gwilt, 2014). The process typically designs for a general market's needs grouped together to create a particular style, while individual needs are ignored (Gwilt, 2014). The main issue with the traditional apparel design process may be that it uses a mainstream target market to design, and lacks a user focus that other disability apparel design processes have implemented into their models. This may be one reason the industry is failing to meet the needs for PLWD, because their needs may be overlooked entirely. The traditional process and current apparel industry designs with aesthetic and expressive values in mind, but there has continually been a lack of focus on social and expressive values in the marketplace (Gwilt, 2014).

It may be advantageous for the apparel industry to consider implementing techniques or changes to the traditional design process to meet the needs of all consumers (Story et al., 1998). Ready-to-wear apparel for the traditional design process looks at specific mainstream, target market's needs and designs apparel for a general population, but a 'one-size fits all' mentality for apparel is not realistic (Suh et al., 2010). Apparel is a basic necessity and a social standard, and consumers should no longer be forced to fit into mainstream set of industry standards (Lamb, 2001).

## Current Design Solutions for PLWD

Currently, there are two solutions represented in research to aid in the solution of designing apparel for PLWD: (a) adaptive design and (b) universal design. Carroll and Kincade (2007), Lamb and Kallal (1992), and Watkins (1988) have included and/or modified one or both of these design solutions into their research, but even with strong research emphasis, these processes continue to be unsuccessfully implemented into the apparel industry. Gwilt (2014) asked the question, "…Can products be designed to have added value to the consumer and at the same time contribute to improved outcomes for the health and wellbeing of the user?" (p.25). This section of research explores this question and the possibilities of why these design solutions are not being implemented into the apparel industry.

### Adaptive Design Process

The adaptive design process is a popular solution method for PLWD, especially for apparel products. Adaptive design is defined as, "… the ability to adapt to new requirements and reuse a product and design when circumstances change such as replacing multiple products with one adaptable product with a set of add-on accessories or attachments" (Gu, Hashemian, & Nee, 2004, p. 540). The adaptive design process suggested by Gu et al. (2004) is shown below in

Figure 2. In the 1950s, adaptive design for apparel was developed at the Institute in Physical Medicine in Rehabilitation of the New York College of Medicine with Helen Cookman leading the research (Eggleston et al., 1994). Adaptive design has also been used in areas other than disability and clothing barrier improvements. Cao et al. (2014) and Gu et al. (2004) both found the benefits of using adaptable design for developing various products for environmental and economic reasons. To aid in the reduction of production and increase the lifespan of a product, adaptable design was coined as a term to help with reviving products in an efficient manner (Cao et al., 2014; Gu et al., 2004).

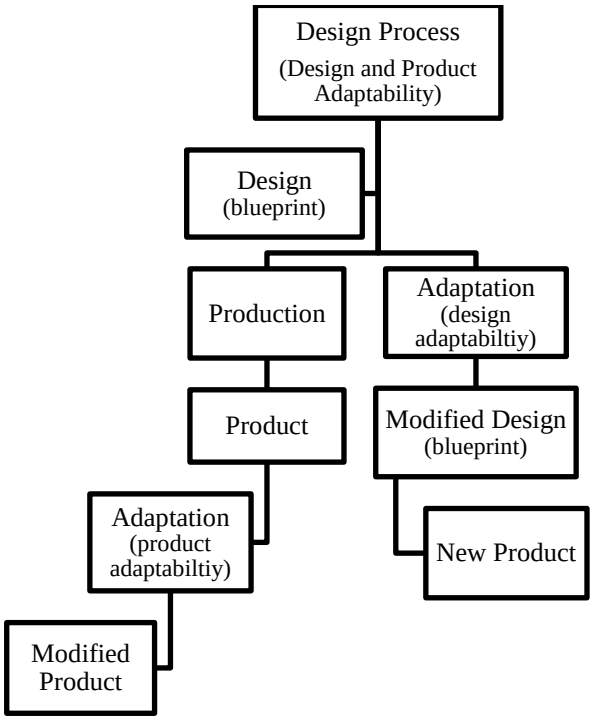


**Figure 2. Adaptive Design Process: adapted from Gu et al. (2004, p. 4)**

**Application.** Adaptive design has been used in the fields of technology, engineering, construction, architecture, and apparel. Adaptive design was originally developed to improve technology, computer systems, engineering systems, architecture, automobiles, and other

transportation (Gu et al., 2004). In the 1950s, adaptive design shifted to the apparel industry with a functional aspect for dress that provided protection and comfort such as: rain coats, boots, ponchos, etc. (Kabel, McBee-Black, & Dimka, 2015). The most commonly known examples of adapted apparel for PLWD in the marketplace are magnet closures, hook and loop closures, easy pull tab zippers, and garments with other openings to ease with donning and doffing of clothing. While these are functionally beneficial for apparel, they are not always the most fashionable and aesthetically pleasing (Kabel et al., 2015).

Overall, adaptive design has remained as a go-to solution to aid people that have disabilities and/or unique needs with dressing. This can be seen in design research for the medical and disabled communities from researchers Kabel et al. (2015); Sau-Fun, Chi-Leung, and Lai-Fan (2011), and Smith (2013). Bye and Hakala (2005) and Cao et al. (2014) both used adaptive apparel design as a focus of their research, but neither used disability participants for their focus. Researchers Eggleston et al. (1994); Gu et al. (2004); Sau-Fun et al. (2011), and Sham Ho, Hyun Jeong, and Ahn (2010) all focused on medical and PLWD needs using adaptive apparel design, but they conducted review and recommendation research. These have been valuable to this study, and they have provided more in-depth knowledge to the process.

Unfortunately, there is a noticeable lack of qualitative and quantitative research related to these design processes and PLWD. Researchers Bye and Hakala (2005) looked at adaptive apparel needs and use for female adult sailors, and Cao et al. (2014) looked at how adaptive apparel design could be a more sustainable design and manufacturing option than traditional methods. While both are useful for the background knowledge of adaptive design of apparel, they emphasize that little research has been conducted for apparel design needs for adult PLWD.

Unlike the other studies, Kabel et al. (2015) performed qualitative research with the aim of documenting clothing barriers for PLWD during social activities. After interviewing PLWD, caregivers, and family members, they found that there is a lack of apparel available, especially for functional, cultural, and sensory related needs (Kabel et al., 2015). Smith (2013) was the only research found that conducted research on hemodialysis patients and clothing needs using adaptive design. Her thesis research focused on existing adaptive apparel and adaptive needs for hemodialysis patients (Smith, 2013). She surveyed a sample of 83 hemodialysis patients, and focused on the attributes of adaptive clothing related to privacy, whether adaptive apparel positively increased integration in social situations, and how the current apparel meets aesthetic needs (Smith, 2013). She found that overall adaptive apparel was perceived positively among the participants, and that social norm integration with the adaptive apparel was significantly influenced on purchase intention, but privacy and the need for symmetry (aesthetics) was not found to influence purchase intention (Smith, 2013).

**Universal Design Process**

Most simply defined, Mace (1985) stated that universal design is a process that creates products that are usable by all without having to adapt or create specialized options and designs (as cited by Park, Morris, Stannard, & Hamilton, 2014, p. 268). Gwilt (2014) stated that this design process ensures that products can serve the widest consumer base possible, no matter the disability, and that it has helped to increase the inclusion of the ageing and disabled populations in America. In the 1970s, Ron Mace, an architect, was credited with coining the term "universal design" (Switzer, 2003). The inclusive process was created out of an idea that there are better ways to design for everyone and include people with disabilities, while creating an affordable and attractable product. The Center of Universal Design created a set of principles for universal

design as a base-line that could be implemented into any industry (Story et al., 1998). The definitions for each principle for the apparel industry, which are adapted from Carroll and Kincade (2007); Martins and Martins (2012); Story et al. (1998) are listed below:

1. **Equitable use** means to create a design that is marketable and useful for all customers without excluding anyone and is aesthetically pleasing for everyone; for fashion this means easy to clean and maintain, and comfortable.
2. **Flexibility** is the accommodation of all consumers' needs and preferences, this allows adaptability for various needs; for fashion this means climate and environment changes, fibers, body temperature, mobility, and other functions.
3. **Simple and intuitive use** is the ability to understand the design and product no matter the intellectual level or skill level and be consistent for all consumers; for fashion this means the ability to dress oneself or with aid related to trims and closures, and donning and doffing of clothing.
4. **Perceptible information** is the communication of necessary information to a consumer no matter the ability, and includes various ways to show the consumer information based on limitations.
5. **Tolerance for error** is the ability to minimize errors and dangers by providing adequate warnings and labels with the product and safety guidelines; for fashion this is comfortable sewing and closures that won't harm skin or irritate, show materials on tags, comfort, well-fitting clothing.
6. **Minimum physical effort** is the part of the design for the product that should allow the consumer to easily use a product without difficulty.

7. **Dimensions appropriate for use and comfort** allows the consumer to use an appropriately sized product per their body and environment.

**Application.** The universal product design process for disabilities was prevalent after transitioning from barrier-free design and implementation of the ADA requirements for architecture and building structures to assist people living with disabilities (Story et al., 1998). There have also been products developed for a medical and/or disability need that have later adapted into inclusive designs. For example, the typewriter, designed in 1843, as an aid for the blind, and the Jacuzzi was originally developed to help with rheumatoid arthritis issues (Shapiro, 1994). The Oxo International company created a line of products called "Good Grips", in 1990, that included utensils and kitchen accessories to aid people with arthritis and dexterity issues (Story et al., 1998). Lever handles, large numbers on appliances and clocks, stairless entry into home and buildings, and curb cuts were all originally created to aid with a disability but have since evolved into everyone's life to make daily functions easier for all (Shapiro, 1994). Since then, universal design has been adapted into other industries and has now provided apparel solutions for PLWD, such as tag-less shirts and Velcro shoes.

Carroll and Gross (2010); Carroll and Kincade (2007); Park (2014) all preformed research that involved PLWD and universal design processes. Carroll and Kincade (2007) applied universal design as a framework for their study on women that worked and had physical disabilities. They found that among their interviews with 9 women and a prototype focus group with 6 women that apparel can be designed to meet various disability needs, which superseded their initial research that stated different disabilities had different apparel needs for each (Carroll & Kincade, 2007). They also found that the working women all had similar apparel needs and wants, and that universal design is a viable option for product development and manufacturing,

but concluded that the industry would be the greatest barrier to successfully implementing the process (Carroll & Kincade, 2007).

Carroll and Gross (2010) later conducted survey research with a similar sample of 117 working women living with disabilities. Their purpose was to further explore the limitations and clothing barriers working women with physical disabilities have and to see if the limitations could predict clothing barrier issues (Carroll & Gross, 2010). They found four distinct physical limitations including: limbs and extremities, core torso, central nervous system, and intellect (hearing and visual) that each effect design, materials performance, and dressing (Carroll & Gross, 2010). They argued that the principles of universal design could accommodate all issues related to the limitations and clothing barriers and that the research could aid the industry to more effectively group and view limitations with their corresponding design solutions (Carroll & Gross, 2010). Limbs and extremities need more focus on dressing and fasteners, core and torso limitation needs more focus on materials, temperature regulation and design, the central nervous system needs a focus on design, and intellect was not significant enough in the results to have design solutions assigned (Carroll & Gross, 2010).

Park (2014) used a three-stage process called, integrative process model for universal design, that combined the principles of universal design and a functional, expressive, and aesthetic attribute model together. Empirical design was used to look at hospital patient apparel and identify user needs; surveys from 173 patients and healthcare providers led to prototype designs of new hospital apparel and showed the benefits of using an integrative process model with universal design (Park, 2014). While these are all strong studies and aid this research study, there is a lack of qualitative interview research for apparel design processes and PLWD. Other research found that aided universal apparel design and PLWD in this section included scientific

lab research such as Curteza et al. (2014), reflections from Martins and Martins (2012), and books from Shapiro (1994); Story et al. (1998). These are all beneficial for this study, but it stresses that there is a continued lack of qualitative and quantitative research based on PLWD and apparel design.

**Issues for PLWD**

While both design processes have been in use for many years, they may not be the most feasible solutions to implement into industry. Adaptive design may be more expensive than universal design to create, produce, and market to consumers. This is usually due to adaptive products can be more difficult to produce in general manufacturing plants, and many apparel companies do not want to custom create products for smaller groups of consumers (Curteza et al., 2014). Kabel et al. (2015) noted that there are barriers and limitations with the ability to sell and market adaptive apparel items to people that have disabilities for reasons, such as limited abilities to go online or take trips into stores, and not being aware a product exists.

The idea of universal design is to include everyone and to implement products that create an easier lifestyle, but this process may not always be achievable. Consumers need to accept the product that is created from any process, especially when using universal design processes; a design not only needs to be socially acceptable it also needs to be designed with the user's wants and needs in mind (Gwilt, 2014). This is can be difficult due to limited feedback and a lack of knowledge about what a consumer may need or want, for universal design (Gwilt, 2014). This study also assumes that this may be an issue for adaptive design products as well, because there is a lack of customer feedback in the development process. The process of universal design is more affordable than adaptive design, but the process can be difficult to continually create products that work for all users (Switzer, 2003). The model for universal design does not include

an outlined product development process for apparel products, so it could cause issues for the industry when adapting it to apparel design. The process of inclusively designing can be a rigorous task to continually create, and adapting current apparel products may be too expensive and/or not aesthetically pleasing for consumer needs.

## Mass Customization

Historically, apparel has been created for an individual and custom tailored to the consumer. Since the 1950s, haute couture and mass produced ready-to-wear apparel have become the norm (De Raeve et al., 2012). The traditional design and production methods may not be the best solution for all consumers, especially for niche markets. Since retailers are facing a challenge with new consumer groups, it would be wise to consider mass customization as a solution for the fit issues related to mass production (De Raeve et al., 2012).

Mass customization began with integration into manufacturing processes in the 1980s, and sparked a shift from mass production to customization options for products (Senanayake & Little, 2010; Silveira, Borenstein, & Fogliatto, 2001). The goal for the apparel industry with mass customization is to create apparel that is more affordable than custom tailored and haute couture designs, while using the basics of the process to have custom fits and styles (Tran, 2015). Mass produced apparel has become the standard to meet consumer needs, but there should be more of a focus on the fit of each human body, rather than trying to use a specific mold (Bye, LaBat, & DeLong, 2006).

**Definition.** Mass customization is defined as "a hybrid of mass production and customization and is a new manufacturing trend. It is an effective competing strategy for maximizing customers' satisfaction and minimizing inventory costs" (Yang, Zhang, & Shan, 2007, p. 167). Mass customization focuses on delivering in a flexible manner at high volumes

and low costs (Silveira et al., 2001). Davis (1987) coined the term mass customization and later Pine (1993) further defined it as "developing, producing, marketing and delivering affordable goods, and services with enough variety and customization that nearly everyone finds exactly what they want" (p.44). Pine (1993) also suggested that mass customization is a new paradigm in which flexibility and quick responsiveness are key for creating customizations. This was similarly compared to Davis' (1987) argument that speed and specificity are the substance for mass customization to be successful. The mass customization process combines two strategies, which includes: mass production and craft production (Blecker & Friedrich, 2006). This combination process can allow companies to maintain lower manufacturing costs, but create a benefit of producing non-standard items through craft production, which entails tailored, customer specific products (Blecker & Friedrich, 2006).

To be successful, mass customization should have the ability to mix individualization with standardized processes (Silveira et al., 2001). Silveira et al. (2001) outlined six internal and external factors for mass customization to be successful, which includes: (a) "customer demand for variety and customization must exist"; (b) "market conditions must be appropriate"; (c) "value chain should be ready"; (d) "technology must be available"; (e) "products should be customizable"; and (f) "knowledge must be shared" (p.4). Lee, Kunz, Fiore, and Campbell (2002) suggested that mass customization may be successful for the apparel industry by improving merchandising errors, forecasting errors, satisfying customer needs, mitigating lost sales, overflows, and no inventory.

Senanayake and Little (2010) found five customization points that include: post assembly, fabrication, feature, fit, and design after conducting a case study on a men's shirt manufacturer. They found that that the turnaround time is about one to two weeks for custom

orders with standard options and three weeks for mass production re-stock (Senanayake & Little, 2010). From interviews they found that mass customization is viable and a few of the key findings include: all points should be at extreme levels of customization or mass production, technology is vital, combine standard options with customization, defined customer base, and limit choices for custom options (Senanayake & Little, 2010).

The consistent challenge when it comes to customizing products is configuring how to keep prices at a similar price point to mass produced products (De Raeve et al., 2012). A possible way to solve this issue may be to use mass customization as a business model to meet consumers' needs (De Raeve et al., 2012). The process of mass customization for apparel may need to pay special attention to the sizes offered, sizing guidelines, and fit models so consumers can order their exact specifications. It may be beneficial to have a standard fit guide, but also have an option to input personal/custom sizing for the designated areas on the body to allow for a better overall fit for a mass customization retailer. Existing companies may have a challenge of properly and successfully integrating mass customization into their existing processes.

Pine (1993) identified five strategies for existing companies to use to properly implement mass customization that include: (a) create customizable services with standardized products, starting with the easiest, (b) create custom products with more individualization options, (c) allow consumer to individualize and design with point of delivery, (d) quick response, and (e) as full mass customization is implemented by using modular components to assemble individual versions of various products (as cited by Duray, 2002; Ulrich, Anderson-Connell, & Wu, 2003). The ability to customize with standard options and pre-designed components can offer a wide variety and lower cost, so the company can be more successful (Ulrich et al., 2003).

Lee et al. (2002) mentioned some challenges for mass customization in merchandising, and suggested that customers may not always be pleased with customized products, which could be a loss due to the item being unsaleable after a return. Some companies fail at mass customization due to unsatisfied customers, it being financially not viable, and unforeseen variables in business with acceptance of customization (Lee et al., 2002). It is important for companies to know their customers and target markets, and have business strategies that work well with mass customization to prevent these potential failures. Lee et al. (2002) surveyed 131 college students about apparel, merchandising, and mass customization, and found that successful mass customization depends on identifying product, process, and place properly.

**Mass customization vs mass production.** Mass production is defined as a way to manufacture and sell goods to consumers in large volumes, while producing efficiently and maintaining reasonable costs for the consumer and company (De Raeve et al., 2012; Pine, 1993). Mass customization is different, in that, a company begins production and manufacturing after an order is placed with specific customizations; the company should be organized and have an efficient supply chain to maintain mass production costs (De Raeve et al., 2012; Pine, 1993). Mass production aims to produce and manufacture standardized, long-life products, but mass customization has a unique ability to produce with shorter cycles for the overall development process and less standardized products (Anderson-Connell, Ulrich, & Brannon, 2002; Kincade et al., 2007). Mass production places customers at the end of the value chain, whereas mass customization places customers right into the product development process at the beginning (Anderson-Connell et al., 2002; Davis, 1987; Kincade et al., 2007; Pine, 1993; Senanayake & Little, 2010). Senanayake and Little (2010) stated that placing customers in a place where they have higher involvement with the design and creation process of apparel can influence their

feelings toward the product, involvement, and purchase intention. Although, mass customization can be more complex and more difficult for existing companies to implement than mass production (Anderson-Connell et al., 2002; Davis, 1987).

Mass customization allows companies to produce only the garments needed and desired, so there is less likelihood of turnover or not meeting the estimated demand (De Raeve et al., 2012; Pine, 1993). Mass production can hurt the apparel industry, especially for the fashion conscious shoppers, because using mass production instead of customization can cause a lack of flexibility with the production of products (Pine, 1993). Davis (1987) suggested that apparel companies can use mass customization for fabrics, colors, and the style for products. Mass customization aims to give every customer, the ability to have custom made apparel that was historically only for the upper classes of society (Anderson-Connell et al., 2002). Pine (1993) suggested that for the apparel industry and other similar industries the next step will be mass customization, because many already use quick response in their value chain, which is defined as having "the right product at the right place at the right time at the right price" (p.191).

**Application.** The model of mass customization is relatively new for the apparel industry, and few companies have successfully implemented the strategy, but automobile, technology and computer companies have successfully been using the process for many years now (Davis, 1987; Hyun-Hwa, Damhorst, Campbell, Loker, & Parsons, 2011; Lee et al., 2002; Pine, 1993). Over time, agriculture harvesting machines, automobiles, transfer trucks, commercial airplanes, elevators, computers, hardware technology, and buildings have all used the process of mass customization successfully (Davis, 1987; Pine, 1993; Tseng & Piller, 2010). Davis (1987) also discussed companies and brands that use customization, which includes: Cabbage Patch Dolls, the Japanese housing industry, service industries, navigation maps, customized television

advertising and local programming, restaurants like Benihana, and newspaper advertisements with regional sections.

Although it is relatively new for the apparel industry, companies such as Land's End, Levi Strauss, and Adidas have implemented small customization and personalization features of products on their websites, even if for only a short promotional period (Bae & May-Plumlee, 2005; Hyun-Hwa et al., 2011; Pine, 1993). Little research has been conducted for mass customization and apparel, but it was suggested by the Textile and Clothing Technology Corporation that mass customization can be implemented into personalization, design, and/or fit for the apparel industry (Bae & May-Plumlee, 2005; Senanayake & Little, 2010). Gilmore and Pine (1997); Tran (2015) suggested four main approaches to use mass customization processes for the apparel industry:

- Adaptive customization (garments modified to meet a specific need for a consumer)
- Collaborative customization (co-design process with conversations between consumers and designers to share needs and wants with garments and most often used)
- Cosmetic customization (one standard product used to sell but is packaged and advertised differently to each consumer)
- Transparent customization (observation of the consumers' needs but the consumers are unaware they receive individualized products)

Senanayake and Little (2010) stated in their research on mass customization and apparel that there are two types of customization for apparel: occupational-customized and consumer-customized. Occupational-customized apparel examples include sports uniforms, monogramming, occupation uniforms with customization, etc. (Senanayake & Little, 2010).

Consumer-customized apparel examples include made-to-measure, specific customization options, print and/or design customization, etc. (Senanayake & Little, 2010).

Anderson-Connell et al. (2002); Kincade et al. (2007); Tran (2015) all conducted varying studies related to mass customization and the apparel industry. Anderson-Connell et al. (2002) researched consumer interest and potential barriers on the implementation of mass customization into apparel manufacturing and retailing. Through focus groups, a consumer driven model was created from the feedback. Their feedback expressed frustrations with standardized fit and sizes of garments, confidence in ability to "design" the apparel, but there was significant interest in the idea of mass customized apparel (Anderson-Connell et al., 2002). Kincade et al. (2007) performed a case study with focus groups on the topic of concurrent engineering and mass customization. The goal was to find out if concurrent engineering could aid in the adjustment of the traditional design and development process for the apparel industry to a more consumer-focused process (Kincade et al., 2007). Kincade et al. (2007) found that this is a viable method to help the apparel development process become customizable, and that the sequential, traditional process does not have to stay sequential.

Tran (2015) conducted research similar to Anderson-Connell et al. (2002) on consumer attitudes and customized apparel products. The research found "the higher the need for uniqueness and apparel involvement level, the more likely the consumer will have a favorable attitude toward customized apparel" (Tran, 2015, pp. 37-38). Tran (2015) also emphasized that from the results, retailers that have unusual or original clothing should highlight those special attributes to their consumers. Body and sizing with standard size guides are not always seen as a positive for some consumers that do not fit the standard size in ready-to-wear apparel, so offering a customizable sizing guide created a more positive attitude for shopping and purchase intention

in the sample from Tran (2015). This enhances the objective that consumers with special and unique needs may prefer customized apparel over the standard ready-to-wear versions.

**Gap for PLWD**

Currently, there is little academic research on PLWD and mass customization apparel, and even fewer on apparel companies targeted at PLWD that offer customization features. In the fashion industry, there is a lack of focus on specific target markets, especially for PLWD (Ashdown & Dunne, 2006). This study assumes that due to the lack of research, body fit knowledge, and specific needs for various disabilities, companies may not be able to afford to take on the process of implementing or starting such a company. "…Many groups are not targeted by the apparel industry and cannot find clothing to fit their proportion and style preferences" (Ashdown & Dunne, 2006, p. 121). Consumers, especially PLWD, want to have a unique and individual look that meets their needs for a garment, and using mass customization allows this to occur at an affordable price (Tran, 2015).

Apparel companies tend to design for the standard, traditional body figure, but this may not be ideal and will not work every body shape and need (Kwong, 2004). Mass customization with a user focused design process appears to be the best solution to meet the consumer's various needs in this target market, while maintaining aesthetics and cost for the consumer and company. A company that desires to implement this type of design and model needs to be willing to take on the user focused design process to meet consumers' needs, include options for customization, and take the time to fully develop a fit guide and customization options for specific target market groups. The options that a consumer living with disabilities might need can be opted-out for someone that is looking to purchase the same garment. This solution meets the needs for target market consumers, while maintaining costs for consumers and the industry.

## User-Oriented Design Process

User-oriented product development began as a human factors ergonomics engineer approach to design products (Kaulio, 1998; Rosenblad-Wallin, 1985). Past literature explained that the user-oriented design was originated by Donald Norman at the University of California in San Diego in the 1980s (Abras, Maloney-Krichmar, & Preece, 2004). Later, the process was established in other fields and industries, including apparel. This research is suggesting the use of user-oriented design to coincide with mass customization as the design process to best meet the consumer's wants and needs.

### Definition

Originally Norman (1988), defined user-centered design as "a philosophy based on the needs and interests of the user, with an emphasis on making products usable and understandable" (p.188). For the purposes of this study, user-oriented design will be the designated term, because Rosenblad-Wallin (1985) used this term when discussing the process for the apparel industry. This study will define user-oriented design as a process that starts with the user's needs and issues, user-analysis and demands form the core for the developmental process, with the key being the use-situation, and different results can occur when using the traditional design process (Rosenblad-Wallin, 1985). The user-oriented apparel product design process, developed by Rosenblad-Wallin (1985), begins with the user's needs and wants related to their functional and symbolic values. Both mass customization and user-oriented design put the customer at the top of the design process, unlike traditional and mass production methods for apparel.

### Application

User-oriented product design has been used in the past in many different fields, and can be adapted to almost any product development. Kaulio (1998) reviewed user involvement in

product development and emphasized that this development theory has been used in areas of ergonomics and engineering, interior design, clothing, hand tools, households and public systems, and transportation. User-oriented design also has a history with technology, computer, and software systems (J. Rubin and Chisnell (2008). The user-oriented design process for apparel design has been mainly used in sportswear and uniforms to provide a function, comfort, support, and mobility to the user (Rosenblad-Wallin, 1985; Suh et al., 2010). Little research has been performed for apparel, user-oriented design processes, and PLWD. Black and Torlei (2013) used this design process for the research and design project of creating a new hospital gown. Gordon (2015) conducted thesis research for breastfeeding apparel with the use of user-oriented design. Thorén (1996) performed a study using user-oriented design for PLWD and their clothing barriers. The study sampled and interviewed 65 participants with disabilities, and found that their requirements for dress depends on their disabilities and includes: fit, function, shopping, and service in-store (Thorén, 1996). Thorén (1996) emphasized that the symbolic values are as important as the functional value, and neither should be overlooked.

**User-Oriented Apparel Design Process**

According to Rosenblad-Wallin (1985), user-oriented product development process was developed and defined by the National Swedish Board for Technical Development (STU) Group on Consumer Technology, the Department of Consumer Technology, Chalmers University of Technology, Göteborg. The design model was constructed for systematic product design, and development focusing on user demands and situations with the end-user in mind (Rosenblad-Wallin, 1985). Rosenblad-Wallin's (1985) research and framework will be used for the framework in this study. This framework was developed with specific steps to design functional clothing using user-oriented design that includes the following:

1. Identification of problem area;
2. Problem analysis;
3. Formulation of objective and project;
4. Formulation of the demands of the user, use-situation, and general demands, based on user studies, interviews, etc., environmental mappings, measurements, and other investigations;
5. Data processing and analysis;
6. Specification of the use-demands and transformation of these into technical terms;
7. Development of ideas and technical solution;
8. Evaluation, modification and selection of prototype;
9. Evaluation of the final solution in relation to the objectives; (p.282)

Rosenblad-Wallin's (1985) design process suggests the use of functional and symbolic values for clothing designed for specific user needs, see Figure 3 and 4. This design process differs from the traditional process at the information gathering stage for research, because the designer and/or researcher needs to look at the specific target market's needs for function related to the clothing (Suh et al., 2010). This process may work well with mass customization of products, since user-oriented design directly focuses on specific target market needs.

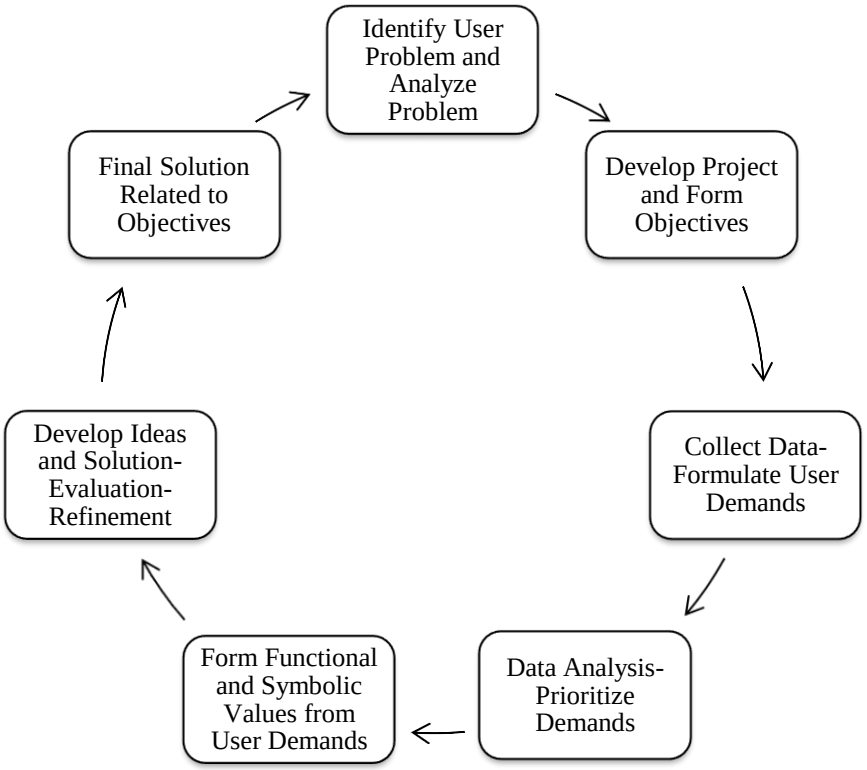


**Figure 3. User-Oriented Product Development Process: adapted from Rosenblad-Wallin (1985)**

**Functional.** Functional aspects of clothing include protection, comfort, mobility, thermal regulation, fit, friction, tactile properties, etc. and are essential for specific target market groups (Rosenblad-Wallin, 1985). According to Rosenblad-Wallin (1985), the most important categories for functional value is comfort and to protect the user of the product. Protective clothing is meant to regulate and protect the end user from their surrounding environments (Rosenblad-Wallin, 1985). Comfortable clothing for the end user deals with the fabric, fit, temperature changes, movement, and tactile needs (Rosenblad-Wallin, 1985).

**Symbolic.** The symbolic aspect of a product is the relation between the socio-cultural environment, the user, and the product; it is the non-material value, where function is the material value of a product (Rosenblad-Wallin, 1985). The symbolic value of clothing focuses on

the psychological aspects of wearing the specific apparel (Rosenblad-Wallin, 1985). These values are related to the user's feelings and expressive attitudes when wearing the product, and the style the product represents; it also deals with the aesthetics and fashion of the product and the style the product carries (Rosenblad-Wallin, 1985).

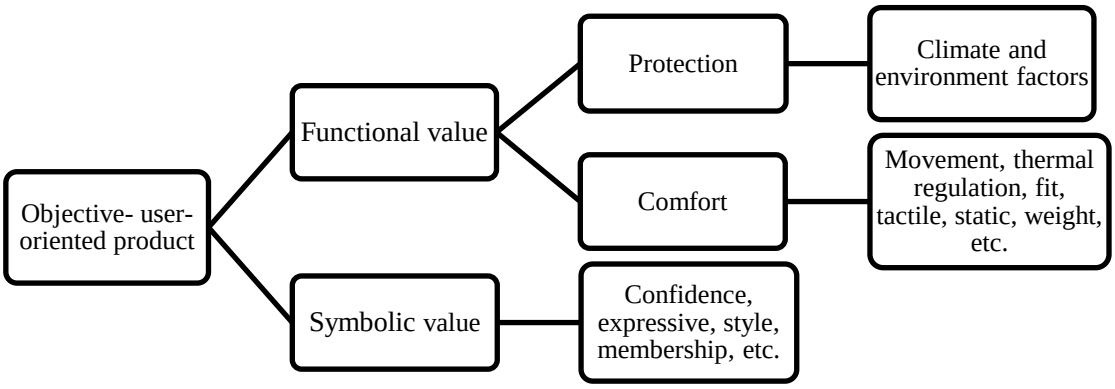


**Figure 4. Connection of the Objective, Functional, and Symbolic Values: adapted from Rosenblad-Wallin (1985).**

## Research Gap and Questions

Historically, apparel has focused on the individual and their needs and wants related to dress, but with the onset of mass production this focus has shifted the individual to the end of the process (Anderson-Connell et al., 2002; De Raeve et al., 2012; Kincade et al., 2007; Pine, 1993). Traditional apparel design, while a standard and systematic process, may not be a viable option for every consumer (Kincade et al., 2007; Senanayake & Little, 2001; Suh et al., 2010). The apparel industry has continually failed to meet the functional and aesthetic needs for PLWD (Gwilt, 2014; Suh et al., 2010). A gap in the apparel industry and a major target market that includes 56.7 million people in the United States that have been diagnosed with a disability, 550,000 of which had kidney disease with renal failure, which results in dialysis, in 2010 (Brault & Census, 2012; Smith, 2013). In the past, there have been some apparel lines created to meet

PLWD and their functional needs, but most fail to include the aesthetic needs and none are developed in the mainstream industry using mass production processes (Gwilt, 2014; Smith, 2013). Even though there are some existing apparel lines for PLWD, there are currently no mainstream retail companies that exist for this underrepresented market (Gwilt, 2014). This research aims to explore this problem and find design solutions to aid in more cohesive inclusion for PLWD and the apparel industry.

Past research on PLWD and apparel has focused on two new design processes: adaptive or functional and universal design processes. While both are practical options for designing apparel for PLWD, they may not be the best option. Adaptive design tends to be more expensive and more difficult to sell than traditional or universal design, due to changes in manufacturing plants and customizing new products that differ from the original (Curteza et al., 2014; Kabel et al., 2015). While seamless in theory, universal design can be difficult to achieve creatively when designing products and there is no defined product development process (Switzer, 2003). Universal design is the better option when designing for PLWD, due to its originality and functionality, but it is difficult to implement in companies and there are currently only a few successful universal products in the market. Even with these options, there is still a gap for PLWD and apparel designed for their specific functional and aesthetic needs. This research wants to consider why this is, and what a better design solution will be.

This research believes that mass customization with a user-oriented design focus may be the solution for designing apparel for PLWD. Mass customization takes the design process back to its historical roots of dress makers and tailored made clothing before the 20$^{th}$ century (De Raeve et al., 2012). Mass customization nixes the standard fit and specific mold the apparel industry currently uses with mass production methods (Bye et al., 2006). In addition, mass

customization combines mass production and customization in a way that allows for standard customization options with apparel but maintains a mass-produced cost for the garments (Blecker & Friedrich, 2006; Pine, 1993). The user-oriented design process focuses on the consumer and their specific needs, unlike traditional and mainstream design apparel (Rosenblad-Wallin, 1985). This process focuses on functional and symbolic values (aesthetic, expressive, and social needs) to aid in the design process for specific users (Rosenblad-Wallin, 1985).

Currently, there is little academic research on mass customization and user-oriented design for the apparel industry connected with PLWD. User-oriented design combined with mass customization may fill in the void between PLWD and the lack of apparel available to them. PLWD, and it is assumed most consumers, want apparel that fits, meets their style requirements as well as meets their functional needs (Tran, 2015). This has failed to be met for years with the traditional design process and mass production manufacturing, and has not improved with the implementation of adaptive and universal design processes (Curteza et al., 2014; Kwong, 2004; Story et al., 1998; Suh et al., 2010).

The objectives of this research are (a) to understand the users' apparel needs and wants, which for this study will be PLWD, specifically people on dialysis and (b) to apply the users apparel design needs and wants to design and develop clothing that can be mass-customized. This niche user not only has apparel needs while having a dialysis treatment, but also in their day-to-day routines and activities. Since hemodialysis is usually conducted in-clinic, there are expected to be needs for apparel that is appropriate for public use, comfort, and maintains sanitation, concealment, and modesty. Peritoneal dialysis is usually conducted at home, so it is expected to have apparel needs of sanitation, protection, and comfort. Vascular access sites for dialysis patients usually includes the upper arm, neck, and legs (Smith, 2013). The vascular

access site needs to be exposed during treatment, so this will need to be considered when designing apparel for this niche market.

Approximately 18.9% of Americans on dialysis are in the age range of 18-54 and are still employed (Smith, 2013). Their employment activities may also need to be considered, when designing apparel options for them. This study is aiming to fill the gap for this niche user market related to the apparel design and manufacturing processes using mass customization and user-oriented design. The research questions for this study include:

**RQ1:** To understand how the traditional design process and mass apparel production are failing to meet the clothing needs and wants of PLWD, specifically for people on dialysis.

**RQ2:** To explore how the current design processes could be adapted to incorporate the user-orientated design process for mass customization of clothing for people on dialysis.

**RQ3:** To apply the user-oriented design process for mass-customization to the clothing needs and wants of people on dialysis, and create suggested clothing products and product distribution channel for this target market.

# CHAPTER 3

# METHODS

Chapter 3 contains the following sections (a) research design, (b) researcher's reflexivity, (c) case selection (d) data collection, (e) validation strategies, and (f) data analysis.

## Research Design

The aim of this study was to gain a deeper understanding of apparel needs and wants of dialysis patients using the user-oriented design process, which discovered the user's functional and aesthetic (symbolic) values, and designed apparel that could be mass customized. Qualitative research was used for the study, because it was deemed the most appropriate method for studying groups or populations of silenced voices, i.e. PLWD. (Creswell & Creswell, 2007). Creswell and Creswell (2007) noted the importance of using multiple data collection methods for qualitative research. Semi-structured, in-depth interviews and observations were utilized to collect data. A design researcher's notebook was used to capture the design process of creating garments for this target market.

Qualitative studies are related to the understanding of specific groups, individuals, moments, the depth of a subject, and focusing on the experiences of the living surrounding the research (Daly, 2007; H. J. Rubin & Rubin, 2011). This type of research is used when studying complex issues that have inadequate theories or do not exist for specific populations (Creswell & Creswell, 2007). A thorough review of literature determined that past design research has not incorporated both user-oriented and mass customization to design clothing for PLWD. Many studies related to PLWD and clothing barriers has solely focused on reviews, opinions, and

quantitative research. The choice of qualitative research was based on past studies from Bye and Hakala (2005), Carroll and Kincade (2007), and J. Rubin and Chisnell (2008) who performed similar exploratory studies to this study. Rosenblad-Wallin (1985) also suggested a series of qualitative data collecting methods to use along with the user-oriented design process. The method collection and analysis followed the method of user-oriented design implemented by Rosenblad-Wallin (1985) as a framework for the study. This method is depicted in Figure 3.

**In-Depth Interviews**

The objective (a) to understand the user's apparel needs and wants, which for this study was dialysis patients, was achieved with semi-structured in-depth interviews. Semi-structured in-depth interviews allowed the researcher to prepare a set of open-ended questions in advance, but allowed for modification and follow-up questions during the interview to gain further insights (H. J. Rubin & Rubin, 2011). Interviews have been found to be a critical part of user-oriented design for products, and are recommended to discover participant's use-demands (Rosenblad-Wallin, 1985; J. Rubin & Chisnell, 2008).

As with all research methods, there are strengths and weaknesses when conducting qualitative interviews. Semi-structured interviews have the ability to adapt and change as needed, and the allow the participant to react to questions, which can provide more detailed responses than a standard survey questionnaire (Bell, 2014). Some weaknesses to interviewing include: it may be more time-consuming, subjective manner may lead to biases, analysis issues can occur, and issues with question wording for the response needed (Bell, 2014). Since this study was exploratory and low risk for participants, eliciting honest, and detailed responses was not an issue. Participants that were more reserved were asked follow-up and more probing questions to

produce more in-depth responses. There was bias with the researcher and subject, but this was written out in the reflexivity and was placed to the side during interviews to remain un-biased.

For this research, interviews aimed to identify problems for dialysis patients, discover their functional and symbolic values, and prioritize their use-demands for designing a prototype. The probes were developed from gaps in the literature and the user-oriented apparel design process. PLWD and apparel research has been found to be lacking in qualitative research, especially in this manner, so the interviews remained reflective and open-ended to gain more insights on their use-situations and demands. Due to the nature of this study being exploratory, most questions explored participant's emotions associated with dialysis, physical feelings during dialysis, and social feelings about being on dialysis. This allowed for more insights about the participant sample and their use-situations. The questions dwelled deeper to gain insights surrounding their apparel use-demands, i.e. functional and aesthetic (symbolic) values, and explored their opinions about mass customization apparel. Table 1 (p. 40) illustrates the interview instrument and probing questions that was used for the study.

## Interview Instrument

### Table 1. Initial Interview Questions

| Central concepts of user-oriented design and research questions | Questions to address each concept |
|---|---|
| **RQ1: To understand how the traditional design process and mass apparel production are failing to meet the clothing needs and wants of PLWD, specifically for people on dialysis.** | |
| Use-situation | How long have you been on dialysis? Where is your site access site located? How you feel about where the access site is located? Tell me about how your experience since starting dialysis treatments. Tell me about your emotional feelings when you receive treatment. Tell me about your physical feelings when you receive treatment. Tell me about your occupation. Tell me about your daily activities and life outside of dialysis treatments. |
| Use-demand | What do you usually wear when you receive treatments? Tell me about what you look for in your apparel when shopping. Tell me about how your access site influences your clothing purchases. Describe a clothing item you have purchased and did not like. Why? Describe a clothing item that you have purchased and did like. Why? Do you have any issues with donning and doffing clothing? |
| **RQ2: To explore how the current design processes could be adapted to incorporating the user-orientated design process for mass customization of clothing for people on dialysis.** | |
| Functional needs | Tell me about an issue you face related to dialysis and apparel. What are the important physical properties of a garment for you? What issues do you have with the current apparel you wear to dialysis and in day-to-day activities? Tell me some of your functional apparel needs you have noticed since starting dialysis. Are you aware that there are online retailers that sell apparel for people with access sites? If so, what companies? Have you owned this apparel? If so, what did you order? What is your opinion on it? |
| Aesthetic wants | How do you feel when you wear the same clothing for treatment in daily activities before/after receiving treatment? Do you feel you dress more related to function or style? Do you feel your culture influences your apparel purchase decision? If so, what does that include? What brands do you look at, do you look at clothing online, Pinterest or Instagram, blogs What kind of clothing or style do you idealize. Do you have a celebrity that you like their style? How fashion involved do you think you are? |
| **RQ3: To apply the user-oriented design process for mass-customization to the clothing needs and wants of people on dialysis and create suggested clothing products for this target market, as well as, a user-friendly product channel.** | |
| Prioritize user demands into functional and symbolic values | Describe your ideal outfit for dialysis treatments. Describe your ideal outfit for day-to-day activities and your occupation. Tell me where you purchase your apparel, i.e. in-store, online, catalogs? Have you customized or adapted any apparel to better meet your needs? Describe to me how you have tailored or altered any of your garments? What are your feelings about having the ability to customize your apparel to meet your needs? Have you customized any of your clothing through online retailers? Describe. Would you customizing your clothing online if you had that option, tell me how you would like that to work? |

**Field Observations**

Field observations took place in certain dialysis clinics in the waiting area during hours of operation. Due to HIPPA (Health Insurance Portability and Accountability Act) violations, observations were not allowed during operating hours in the treatment area with patients. Participatory observations of participants were conducted for in-person interviews, as well. Bye and Hakala (2005)) iterated that participant observation is vital for understanding user needs and wants associated with apparel, and allows the researcher to gain skills to more effectively interpret the data collected during the analyze portion of research. To gain deeper insights into the emotions of the participants and their apparel needs and feelings about mass customization, participatory observation was used in addition to interviews. An observation protocol was used for field observations, because it aided with recording information and staying on track, refer to Table 2 (Creswell & Creswell, 2007).

**Table 2. Observational Protocol adapted from (Creswell & Creswell, 2007)**

| **Length of Activity:** | |
|---|---|
| **Descriptive Notes** | **Reflective Notes** |
| Record description of (activities, temperature, colors room, material of furniture, differences, similarities, environment, windows, art, wayfinding, space, set-up) | Notes for process, reflections, and summary |
| Location: Waiting Area | |
| Location: Clinic Treatment Area | |
| Location: Interview location | |

There are some potential disadvantages when conducting observations that include: bias from the researcher, researcher may be treated as an outsider, overlooking behaviors that would be seen from someone that is not experienced in the related field, and consent needed from the participants (Bell, 2014). This study took into consideration biases that could occur during observation. Since this study was low risk and there was a lack of knowledge and experience in the observed environments, these disadvantages did not directly apply to this study. During field observations, the researcher did not appear to be an outsider, because there were other patients and caregivers in the waiting area. While there were some disadvantages, the advantages for this study outweighed them. Advantages to participatory and field observation included: learning more about the participant group and their lives and activities outside of the interview questions, body movements, emotions, impressions, issues related to their dialysis treatments and other possible disabilities, and observation of current apparel worn for treatment and daily activities (Bell, 2014).

To collect the observations, jot notes and a design researcher's notebook with fieldnote write-ups were used during the data collecting process. Jot notes are a way to initially record information about the interview and observations (Creswell & Creswell, 2007). They allow the researcher to note what is happening in their surroundings, and how the participant is responding without distracting from the interview or environment surrounding the researcher. Fieldnotes in a researcher's journal aids with fleshing out jot notes to turn them into a detailed analysis of the observations (Emerson, Fretz, & Shaw, 1995). Jot notes were used to describe the participants body language, attitudes, the environment, and the researcher's personal feelings, which led to deeper insights about the participant group and dialysis clinics. After the interviews, the

researcher immediately added follow-up notes and details to the observation notes to maintain the most efficient memory and knowledge as possible.

**Design Researcher's Notebook**

Design research is defined as a process that uses precise, thorough inquiry to analyze and discover new ideas and information, with the use of emotion by the researcher (Bye, 2010). This type of research is often used for unfamiliar areas and specific problems that are unable to be easily solved with the use of science, engineering, or simple design processes alone (Bye, 2010). Armstrong (1999) stated that the use of a notebook for a design researcher is critical, and it is an important reflective process that details how responses, places, and observations evolve into a final design. The purpose of the notebook is to aid in the validation of the research, organize the researcher's raw data, design, and thought processes (Frugoli, Etgen, & Kuhar, 2010). This type of research is vital for this study, because the focus is an under researched area and problem that may not be solved with science and engineering alone.

For the design research process, a design researcher's notebook was used to organize raw data from the researcher and aided the researcher's design idea process. Frugoli et al. (2010) suggested using a physical notebook to make hand-written notes with page numbers to keep the notebook organized. The researcher followed these suggestions, and used a notebook to keep all hand-written observed data, reflections, ideas, and sketches. The researcher's notebook was used to record the process of design ideas and possible solutions by the researcher throughout the study. The design researcher's notebook was also used by the researcher to record the researcher's personal reflections on participatory and field observations, and jot notes and field notes from observations.

## Researcher's Reflexivity

Johnson (1997) and Yin (2011) both emphasized that a researcher's reflexivity is of critical importance when validating qualitative research. A "critical self-reflection" must be performed by the researcher in order to acknowledge potential bias and perspectives that can affect the data gathered by the researcher (Johnson, 1997). For this study, a reflexivity will allow the researcher to be more self-aware and allow the researcher to more effectively control for potential bias in the research (Johnson, 1997).

I, the researcher, have a unique and personal insight related to disability apparel and the participant group chosen. I have had family members and close family friends that have been or are currently on hemodialysis or peritoneal dialysis. My family also has a close connection with a nephrologist physician, who specializes in kidney disease and dialysis. These connections and firsthand knowledge and experience with this group has led me to conduct research for dialysis patients. After a conversation with the nephrologist and the issues dialysis patients go through during and after their clinic visits, I was inspired to research this underrepresented group. I also discovered during my research that similar issues occur for chemotherapy patients, children with cancer, and anyone that needs a vascular access site. I was even more inspired to research how clothing can improve their lifestyles and ease any burdens in their life related to their illnesses.

I know from my personal experience that being extremely cold during and after treatment is a widespread issue for many people. The main issue is that ports must be visible during dialysis, so short sleeves or other clothing needs to be worn, even in the winter. I have also noticed a need to keep access sites clean, covered, and protected. Access sites can bleed out easily, especially if they are bumped too hard on a surface or someone grips around the site. I have also found from my personal connections that many have other disabilities or issues that go

along with their dialysis, so this research may lead to more issues and design solutions than for dialysis patients alone.

I recognize my bias in my personal knowledge and opinions on issues that exist for dialysis patients, and how these connections could be a limitation and influence my interpretations and results. However, I believe these personal connections and previous knowledge gives me an extra advantage and deeper insights to these underrepresented groups. Even though I have not been on dialysis or needed a vascular access site, my experiences and connections allow me to have a unique advantage to see and notice issues that others, who are less experienced with this group, may overlook. I realize I need to be self-aware throughout the study to avoid creating my own assumptions, and the use of a personal journal will aid as a reflection on my ideas for designs.

## Case Selection

The method of purposive sampling was chosen for this study. The sample of participants was chosen, since they were either a dialysis patient, an in-clinic worker, and/or a caregiver to a dialysis patient. This method of sampling is used in selecting participants that have a range of specific experiences, roles, and socio-demographic characteristics within the phenomena being studied (Ritchie, Lewis, Nicholls, & Ormston, 2013).

After approval of the university's Institutional Review Board (IRB), a total of fifteen participants were recruited through emails and recruitment flyers in-clinics and online dialysis support groups. All participants lived across United States during the time of the data collection. Participants were either currently dialysis patients (peritoneal or hemodialysis), recent kidney transplant recipients, in-clinic dialysis workers, and/or caregivers to an immediate family member on dialysis (peritoneal or hemodialysis). Variations of participants recruited was chosen

because it allowed for different perspectives on apparel needs and wants and dialysis issues. The participants' ages ranged from 30 to 66, and there were eight females and seven males (including caregiver's husbands on dialysis). There were two recent kidney transplant recipients, three caregivers to their husbands on dialysis, and ten current dialysis patients interviewed. One of the caregivers was also an in-clinic dialysis dietician. Occupations for the dialysis patients included: volunteer work, salesperson, counseling therapist, food service at a school, business owner, stay at home wife, retail associate, and at-home customer service representative. Five participants noted that they were unemployed and did not have any active social activities, such as a stay at home wife/husband or volunteering. Three participants indicated that they did not have to work, but that they were stay at homes wives and mothers and enjoyed volunteer work and other social activities.

Dialysis patients (current and recent kidney transplant recipients) time on dialysis ranged from 11 months to 16 years. Current access site locations for dialysis patients (including caregivers interviewed) included: five dialysis patients with a left forearm access site, three with an upper left arm access site, one with a right forearm access site, three with an upper right arm access site, two with an upper chest access site, and one with a peritoneal stomach catheter. It should be noted that these were participant's current locations, but many had other access sites in the past. The current type of dialysis treatment participants were on included: eight at-home hemodialysis patients, six in-clinic hemodialysis patients, and one peritoneal dialysis patient. It should be noted that these were the current locations participants were receiving treatment, but many had different types of dialysis treatments in the past. Table 3 illustrates detailed demographic characteristics of the participants recruited.

## Table 3. Demographic Characteristics of Participants

| Participant[1] | Age | Gender | Ethnicity | Marital Status | Children | Occupation | Time on Dialysis | Current Access Site | Type of Dialysis |
|---|---|---|---|---|---|---|---|---|---|
| Patrick | 36 | Male | Caucasian | Engaged | No | Part-time office work, full-time student | 8 years | Left forearm-fistula | At-home hemodialysis, PD |
| Lauren | 30 | Female | Caucasian | Married | No | Stay at home wife-volunteer work | 5 years, 7 months | Left forearm-fistula | In-clinic hemodialysis |
| Ashley | 58 | Female | Caucasian | Married | Yes, 5 | Customer Service Rep at home, volunteer work | 15 years | Upper left arm-fistula | In-clinic & at-home hemodialysis |
| Henry | 56 | Male | Caucasian | Single | No | N/A | 6 years | Right upper chest catheter | In-clinic hemodialysis |
| Stacy | 54 | Female | Caucasian | Married | No | Full-time clinical counseling therapy worker, part-time in-home therapist for children | 3 years/ transplant recipient | Left forearm-fistula | In-clinic hemodialysis |
| Ann | 34 | Female | Caucasian | Widowed | No | *caregiver* N/A | Husband on dialysis for 2 years | Chest catheter | At-home hemodialysis |
| Catherine | 51 | Female | Caucasian | Married | Yes, 2 | Full-time food service at a school | 2.5 years | Left forearm-fistula | In-clinic hemodialysis, PD |
| Sarah | 50 | Female | Caucasian | Widowed | No | N/A | 4 years | Upper left arm-fistula | In-clinic & at-home hemodialysis |
| David | 31 | Male | Caucasian | Married | No | Full-time salesman | 11 months/ transplant recipient | PD stomach catheter- right side below belly button | PD |
| Carol | 52 | Female | Caucasian | Widowed | Yes, 10 | *caregiver* N/A | 7 years | Left forearm-fistula | In-clinic hemodialysis, PD |
| Andrea | 53 | Female | Caucasian | Married | Yes, 1 | Stay at home wife | 16 years | Upper right arm-fistula | In-clinic & at-home hemodialysis |
| Rachel | 56 | Female | Hispanic | Single | Yes, 1 | N/A | 3 years | Left upper arm-fistula | In-clinic hemodialysis |
| Phillip | 57 | Male | African-American | Married | Yes, 3 | Owns a travel agency | 6 years | Right upper arm-fistula | In-clinic & at-home hemodialysis |
| Jennifer | 55 | Female | Caucasian | Widowed | Yes, 2 | Part-time retail associate | 1 year | Upper right arm-fistula | At-home hemodialysis |
| Linda | 66 | Female | Caucasian | Married | Yes, 2 | *caregiver* dialysis clinic dietician | Husband on dialysis for 2 years | Right lower arm- fistula | At-home hemodialysis |

*Note.*[1] All Participants' names are pseudo names.

## Data Collection

In order to strengthen the design of this study, data triangulation was used to study the phenomena at hand. The study entailed three steps for data collection: (a) in-depth interviews, (b) observations, and (c) design researcher's notebook. The researcher conducted two in-person interviews at the location of the participant's choice, and conducted the other thirteen interviews over the phone. Throughout the in-person interviews participatory observations were made, and jot notes and personal thoughts were recorded during phone interviews in the researcher's notebook.

Due to the requirements of the university's IRB, informed consent forms were created to give the participants information on what the interview process would entail, ensure confidentiality, and get approval to audio record them during the interview. The word usage of the consent form was in common English, both clear and concise, as to be understood by anyone. A sample of the consent form is provided in Appendix B.

### In-depth Interviews

After approval was received from the IRB, the researcher began sending out recruitment emails to three doctor's offices and seven dialysis clinics in the Athens and Atlanta, GA area. The email and flyer recruitment documents are in Appendix C and D. Two participants were recruited from personal connections to the researcher, and in-person interviews were conducted. There was a lack of feedback from the recruitment flyers in dialysis clinics. Due to a time commitment for this study, the researcher altered the methods of collection in IRB and posted recruitment flyers on four online dialysis patient support groups on Reddit.com and Facebook.com. The remainder of participants were recruited from online support groups, and phone interviews were conducted. The change in recruitment allowed the researcher to interview

a greater variety of participants across the United States, and the main disadvantage was the inability to conduct more participatory observations.

Once the participants contacted the researcher, interview times were scheduled based on the set preliminary questions to ensure they met the requirements to participate in the study. The date and times for interviews were based on convenience of the participants. The two in-person interviews were conducted in coffee shops, and the rest were over the phone. The interviews took place at various dates and times during the month of March. The interview duration for participants ranged from 20- 105 minutes.

Before the interviews began, participants were given a copy of the consent form to review and sign. After an explanation of the study, confidentiality agreement, and audio-recording permission, participants signed the form. The phone interview participants were emailed copies of the form, and either emailed or mailed a signed copy back to the researcher. Interviews began with the researcher asking a series of demographic questions that included: age, gender, marital status, occupation, years on dialysis, type of dialysis, access site location, etc. Since the interviews were semi-structured, all participants were asked the same initial questions. The initial questions were used for demographic information and to begin to develop the use-situation. The interview questions followed the user-oriented design process with the goal of discovering use-situations and demands related to apparel.

The next set of questions focused on developing the use-situation and begin discovering demands related to their clothing needs and wants. Participants were asked questions about their feelings about dialysis, both physical and emotional. They were also asked about what they wore to dialysis and in their daily activities. These questions were meant to discover the various environments participants were in for dialysis and their day-to-day life, and how their clothing

effected their physical and emotional feelings in both situations. Participants were asked how they felt about wearing the same apparel to dialysis and to their day-to-day activities, which was meant to evoke a sense of separation in their wardrobe. Participants were also asked to tell about their shopping habits, and how dialysis effected what they look for in clothing. This was to see if they shop more online or in-store, and what they typically shop for related to apparel.

The next set of questions focused on determining participant's functional needs and their aesthetic wants for apparel. The participants were asked to tell a story about a time that their apparel did not work with their dialysis treatment to see if there were other issues related to dialysis and clothing that were not previously discovered. Individual stories allowed for personal and unique information that might not have been discovered with general questions. Participants were asked about what they looked for physically in garments, i.e. closures, fabrics, colors, length, etc. Culture was discussed in this section to see if their culture influenced their purchase decisions related to modesty, colors, etc. Participants were asked if felt they dressed for function or style and then asked to elaborate to elicit responses on what they feel they purchase and look like versus how they would like to dress and look like. Finally, they were asked about brand preference, style preference, and if they look at clothing online or follow any celebrities to see how fashion oriented they were.

The last section was meant to prioritize their demands for their ideal apparel, and their opinions on customization related to clothing. Participants were asked to describe their ideal outfit for dialysis and one for their day-to-day activities. They were then asked if they had customized any apparel to better meet their needs. If they had or knew someone that had done so, they were asked to describe what was done to customize the garment. They were then asked about mass customization and their opinion on being able to select clothing with set options to

better meet their overall needs and wants. Participants were also asked to give opinions on current dialysis apparel in the market, if they had seen it or purchased an item previously.

## Validation Strategies

The following validation strategies were used to ensure validity in this study (a) triangulation, (b) low inference descriptors, and (c) reflexivity.

The validation strategy of triangulation aims to corroborate themes of what's been reported in the study though different sources of information (Yin, 2011). Triangulation pursues the converging of data and confirmation from three different sources in the collection process (Yin, 2011). Triangulation is an important validation strategy for the design research portion of the study, because it can increase credibility (Bye, 2010). For this study, triangulation data sources that were used included: in-depth interviews, observations, and personal reflections in the researcher's journal. Interviews allowed the participant to have a voice to express their issues related to dialysis and clothing and needs and wants of their ideal apparel. Observations allowed for rich descriptions of the dialysis clinic environments, clothing worn for treatment, and day-to-day activity clothing worn. The researcher's design journal allowed for personal reflection from interviews and observations that added to design ideas and possible solutions to meet participants use-situation and demands for clothing.

Next, low inference descriptors used rich data to ensure detailed and variations in the data collected from observations and interviews (Yin, 2011). This strategy used thick descriptions to describe further details and combine data collected from participants to transfer to other settings and areas in the research and form shared characteristics (Creswell & Creswell, 2007). Direct quotes were pulled from the participant interviews after transcribing and coding the data. The

direct and block quotes from participants were used to further comprehend meanings and feelings of the context presented by the participants.

Finally, reflexivity was used as a validation strategy because the researcher was an active participant in the study. Reflexivity is an important validation strategy to use when performing qualitative research. “How we write is a reflection of our own interpretation based on the cultural, social, gender, class, and personal politics that we bring to research” (Creswell & Creswell, 2007, p. 179). Since the researcher had personal ties, past experiences, and bias to the subject being studied, it was important to have reflexivity as a validation strategy to help the reader understand how it could have affected the study.

## Data Analysis

After the data were collected from the participant interviews and observations, the recorded audio was saved on the researcher’s personal computer and interviews were personally and professionally transcribed. Since transcribing can be a lengthy process, the researcher had six interviews professionally transcribed by Wordsworth Typing and Transcription. The remaining nine interviews were transcribed by the researcher using transcribe.wreally.com. All transcriptions were downloaded and saved on the researcher’s personal computer in Microsoft Word. After the transcriptions were downloaded, the researcher double-checked all transcriptions and added in additional jot and field notes that were not audio recorded. Throughout this process, the researcher began piecing together concepts and noting reoccurring themes that emerged.

Transcripts were coded and interpreted by emerging themes and concepts with the aim of designing a prototype using mass customization options. Following McCracken’s (1988) method, a detailed analysis was used that moved from a specific to a more general process, in which the researcher was fully immersed in the data to find details and then move on to more

generalized observations. The researcher moved from a detailed analysis of each transcript to a general comparison of themes across all transcripts. A cyclical process that began with breaking apart raw data and placing them into themes aided in establishing general themes, which then allowed the general themes to be broken down into smaller sub-themes under them (Creswell & Creswell, 2007).

# CHAPTER 4

# FINDINGS

Chapter 4 contains the following sections (a) dialysis treatment, (b) challenges of dialysis, (c) design of clothing, (d) design solutions.

The findings section is divided into four sections that answer the three research questions of this study. The first section, dialysis treatment, discusses research question 1: to understand how the traditional design process and mass apparel production are failing to meet the clothing needs and wants of PLWD, specifically for people on dialysis. The second section, challenges of dialysis, discusses research questions 1 and 2: to explore how the current design processes could be adapted to incorporate the user-orientated design process for mass customization of clothing for people on dialysis. The third and fourth section, design of clothing and design solutions, discusses research question 3: to apply the user-oriented design process for mass-customization to the clothing needs and wants of people on dialysis and create suggested clothing products and product distribution channel for this target market.

## Dialysis Treatment

By initially exploring the experiences participants had during their dialysis treatments and lives, three theme categories emerged from the interview and observation data, which was the aim of research question 1: to better understand how the traditional design process and mass apparel production were failing to meet the clothing needs and wants of dialysis patients. Following the user-oriented design process, this theme begins to establish the problem area, i.e. use-situation and use-demand. The theme categories that emerged were (a) treatment as “It’s

really an evil path that I'm walking down," (b) physical feelings as "The desire just to rip out the needles and run," and (c) emotional feelings as "This has been one huge roller coaster ride."

For all three theme categories, smaller themes also emerged. The "treatment" theme category included the three themes: (a) in-clinic hemodialysis as "You have no control," (b) at-home hemodialysis as "I have more of my life back," (c) peritoneal dialysis as "Daily monotony." The "physical feelings" theme category included: (a) extreme temperature sensitivity as "I couldn't stop shivering and I almost shook my needles out," (b) immobilized as "Trapped in this chair," (c) exhaustion as "I would be blessed to get home and I would just crawl to bed." Finally, the "emotional feelings" theme category included the themes: (a) "I went through the grief process," (b) "I hate it with everything in me," and (c) "You can always find the good with the bad."

**Treatment as "It's really an evil path that I'm walking down."**

There are three types of dialysis treatments available which include: (a) in-clinic hemodialysis, (b) at-home hemodialysis, and (c) peritoneal dialysis. At-home hemodialysis and peritoneal dialysis are both conducted in the patient's home, while in-clinic hemodialysis is performed in a dialysis medical center or hospital. Even though at-home treatments exist, many patients do not have the option to receive their treatment at home. Dialysis at-home requires storage for "a lot of bags and supplies," and keeping the environment clean and pet free. Rachel, a 56-year-old hemodialysis patient of 3 years, mentioned she could not do at-home dialysis, because she lived alone in a small apartment with a cat. At-home hemodialysis and peritoneal dialysis are less "draining" and "harsh" on the body, because it is performed daily. In-clinic hemodialysis is the harshest treatment, due to taking off larger amounts of fluid every other day.

Henry, a 56-year-old in-clinic hemodialysis patient, described his overall treatment experience as "draining" and "difficult."

> **Henry:** "Physically I'm extremely drained almost to the point that sometimes I'm ready to keel over. It's really an evil path that I'm walking down." "(After dialysis) all I want to do is get home. I'm pretty much in bad shape after dialysis."

**In-clinic hemodialysis as "You have no control."** In-clinic hemodialysis was described as "uncomfortable," "depressing," "draining" and "harsh" on the body, and a "loss of independence." Catherine described her in-clinic experience as "very uncomfortable… so the whole experience is not really something I enjoy… so it brings in some depression." Ann, a 34-year-old caregiver for her husband on hemodialysis, discussed how the "darker" colors worn by patients and the color scheme of the clinic might be depressing to the patients, "I know dialysis patients have to sit in a dark cold room all the time."

Phillip, a 57-year-old hemodialysis patient of 6 years, described the in-clinic machines as "draining", because "you are on there from 3-4 hours… 3 days a week," and that "you are taking off about 2 days' worth of fluid every time." Sarah, a 50-year-old hemodialysis patient of 4 years, described her in-clinic experience as being "wore out," and being so tired she would just go to bed right after treatment. Andrea, a 53-year-old hemodialysis patient of 16 years, started in-clinic, and then went to at-home hemodialysis.

> **Andera: "**I do not like in-unit hemo, because you have no control over your arm or anything or your treatment. Now I feel more positive about it (at-home dialysis), but it's not something I like doing. It's something I have to do, so I just have to do it. I'd rather I didn't have to do it, but I have to do it."

While each clinic is different, all have a similar theme of tinted windows, chilly temperatures, unwelcoming chemical solution aromas, and generic furniture and artwork that mirrors a waiting area in a hospital. Some clinics are newer with soft, high-quality leather chairs,

wood floors, and soft lighting. Other clinics appear as though they are stuck in the 1970s with green and blue color schemes, dated, aging artwork and furniture. Each clinic ranged in physical size of space, but the use of bland colors, large chairs, and the dark windows made each one appear smaller. The emphasis on being a medical clinic and lack of cheerful colors, art, and furniture created a melancholy atmosphere that echoed throughout each clinic observed.

**At-home hemodialysis as "I have more of my life back."** At-home hemodialysis was described as "better," more "relaxing" and having more "freedom" when compared to in-clinic hemodialysis. Even though there are still feelings of "I don't feel like doing it," as Jennifer stated, a 55-year-old at-home hemodialysis patient of 1 year, and "it's not something I like doing, but it's something I had to do," as Andrea described, at-home hemodialysis is "easier on your body," per Linda, a 66-year-old caregiver and in-clinic dietician worker.

> **Jennifer:** "I've only done in-home hemo. I didn't want to do in-clinic. You have so many issues in-clinic. You're on their schedule, but with this (at-home hemo) I can do it when I want. You have your own schedule, and so much more freedom. It's not as draining on your body, because you do it more often. You don't have to take off a lot of fluid at once. If you take on more fluid, you have a problem. But you do what you gotta do."

At-home hemodialysis allows patients an alternative to the in-clinic setting, which allows them to have more "freedom" and "independence." Sarah compared her in-clinic experience as "when you lose your independence" to her at-home hemodialysis experience as "things are getting better, so I can actually enjoy my days' in-between dialysis more." Phillip, who owns a travel agency, seems to enjoy the benefits of at-home dialysis now, because he has more "control" and is not as limited with his time.

> **Phillip:** "To me there's a big difference in doing it in-clinic and doing it at home. There's a drastic difference to me between the two. Being at home is better. Being at home it's more of a relaxing atmosphere. I'm on my own time, so I can do it anytime of the day that I choose to do it. It actually allows me to have more of my life back. I'm not restrained, because I have to go to dialysis. I can't make this appointment at this time because I'll be at dialysis, or I can't do something on Monday, Wednesday, Friday because I'm at

> dialysis. I don't have those problems anymore, and the fact that I have a travel agency I have to do a lot of traveling across the country. It allows me to be able to do that again without having to find a dialysis center wherever I'm going and having to find a time they can fit me in and all of that."

**Peritoneal dialysis as "Daily monotony."** Peritoneal dialysis, by far, was described in the interviews as "not many issues," "felt totally normal," and "easier on the body." Peritoneal dialysis does not filter the blood, and it is performed daily, usually at night, so any fluid that is taken on is pulled off daily, rather than every two days. Issues still arise with peritoneal such as, a 12-15-inch catheter extending from the stomach, storage of supplies, and swelling of the stomach from the fluid, but overall peritoneal appears to be less "harsh" and demanding on the body. Catherine, a 51-year-old dialysis patient of 2.5 years, preferred peritoneal to in-clinic hemodialysis.

> **Catherine**: "I feel horrible, the whole experience is not something I enjoy. Whereas when I did PD at home, I didn't feel this way at all. I felt totally normal."

The issues of adequate storage space, the process of the treatment, keeping the access site clean, and the amount of time on the machine for treatment were expressed by all the patients interviewed that are or have been on peritoneal dialysis. Linda mentioned that this treatment "you have a lot of bags and supplies with PD. You have to have travel bags on hand in case you run out of electricity, so you have to keep extra on hand," but later stated that "it is a little more work at home, but it's worth it because you get better results." David, a 31-year-old dialysis patient of 11 months and recent transplant recipient, did not have many physical side effects, but he did express his frustration with the daily process for his treatment.

> **David:** "I definitely had some trouble sleeping. That was probably the hardest part was not being able to get up and move around while connected. Just the daily monotony of setting up, disconnecting, connecting and doing everything, throwing everything out, and then setting back up, and not being able to just get up and go to bed."

**Physical Feelings as "The desire just to rip out the needles and run"**

The physical feelings that dialysis treatment evokes, regardless of location, is a similar physical experience for all participants. While some had varying or fewer physical feelings, depending on their treatment method, it was almost unanimous that at some point they experienced (a) extreme temperature sensitivity, (b) felt "immobilized" during treatment, and had been (c) "exhausted" on treatment days. Thus, the three themes for "physical feeling" were developed. Sarah, a patient who has experienced both in-clinic and at-home hemodialysis, described the physical feeling of sitting down for treatment as a "fight" and "struggle" every time.

> **Sarah:** "In-center and at home, the one thing that hasn't changed for me in these all these years is the desire just to rip out the needles and run. That's the best way I can explain it, because being tethered and not being able to move, in my case because of my arm length and everything, I have to keep my hand (still) I can't (move) because I'll stop the machine."

**Extreme Temperature Sensitivity as "I couldn't stop shivering and I almost shook my needles out."** Temperature is defined, for this research, as the feeling of being hot or cold for the patients, not just temperature of the environment during treatment. Temperature feelings vary slightly for patients that were at-home versus in-clinic, but almost all had experienced those feelings of "chills" and "shivers" during and after their treatment. Dialysis treatment centers are purposely kept cold for "infection control" and "germs," per Andrea and Phillip. Linda, an in-clinic worker, had a theory for the temperature in her clinic.

> **Linda:** "I think part of the problem is that the techs are running around like crazy and they are hot. They are supposed to wear PPE covers and face guards, and that makes them hot. The patients are just sitting there and they are freezing, and the techs turn the heat down and the patients freeze. It just adds to their coldness. I was often cold when I go into the clinic area too, because I wore a scrub jacket instead of a PPE outfit, because that would keep me warmer."

These clinics are so cold in fact that even while observing on a day in February in Georgia, the facility still ran the air-conditioning. In addition, windows are tinted black, so even the warm sight of sunlight is not allowed in. Even the patients and caregivers observed in the waiting area, kept their jackets on and remained bundled up. Linda described that the patients she had in-clinic would "wear hats to keep warm," and that some would "wear a glove on the hand that doesn't have a fistula" to keep warm. Sarah iterated that "you oughta see some people in-clinic; the things we do to stay warm, but you got to do it," which suggests that patients are desperate to try to stay warm. Linda continued by vividly describing the treatment as "it's very uncomfortable, you are very cold getting all that cold blood put into you, it freezes you inside." Stacy, a 54-year-old dialysis patient of 3 years and recent transplant recipient, discussed throughout her interview the intense cold felt in-clinic.

> **Stacy:** "I was always cold. It was like automatic. They (the nurses) would know. They had the heater on the chair for me. I would shiver though they would have two blankets on me and I would still be cold."

Even those participants that receive dialysis at home with the ability to control their environment, feel this extreme coldness. Ann stated that her late husband, "during the treatments he would get very cold, and he would get under the covers in bed, since we did it at home. Which was good, but he did get extremely cold." Ashley, a 58-year-old hemodialysis patient, dialyzes at home and still has extreme temperature sensitivity, "like right now I'm on treatment and I have been freezing because last night it was 20 degrees out and even though we keep the heat on I still am cold." Sarah experiences not only feelings of cold but also feelings of being hot, even though she has her treatments at home.

> **Sarah: "**I get flushed I get chills and hot flashes, I'll just cycle in and out of them. It's crazy. It drives me nuts… You know it's super cold when I do dialysis and if I'm too cold

> I shiver and I couldn't stop shivering and I almost shook my needle out. I can get the other arm under my blanket and put the blanket over my head and leave my face open, but it would be so nice to be able to cover this arm up."

**Immobilized as "Trapped in this chair."** Frustration from limited limb mobility and being "strapped" or "hooked up" to a machine were felt by most participants, no matter the type of treatment. David described the most difficult part of his treatment as "not being able to get up and move around while connected," while others such as Andrea felt "fidgety" and Stacy who experienced "restless legs… I would have my legs all over the place." Lauren, a 30-year-old hemodialysis patient of 5 years, described her in-clinic time as being "strapped to a dialysis machine for 4 hours three days a week," which many participants described as time dragging on. Patients that have arm access sites often experience issues with limited mobility other than being "strapped" to a machine such as, Ashley who explained that she is "completely immobilized" for the duration of her treatment, because of her arm access site and a blood pressure cuff on the other arm. Sarah detailed out a similar situation with her arm access site and feelings of being "tethered" and "tied down."

> **Sarah:** "The best way I can explain it because being tethered and not being able to move in my case because of my arm length and everything I have to keep my hand (still) I can't. I've noticed in-center that some people can move with their needles and I can't, because I'll stop the machine. So, I literally have that arm tied down by that and my other arm is tied down when my blood pressure is taking every half an hour. I've never been one to sit much, and now I'm trapped in this chair for 3 hours and it drives me crazy! I want it all be over, and I hate it with everything in me. But I fight it every time I get on. I just fight I fight every time I get on you've got to do this or you won't be alive."

**Exhaustion as "I would be blessed to get home and I would just crawl to bed."** Feelings of exhaustion appear to come from the type of treatment, other medical issues, and how much fluid is "pulled off" from the patient during treatment. Catherine explained that her blood pressure would drop during treatment, and that she "felt horrible" after her in-clinic treatment.

> **Catherine:** "(When)I'm at treatment, usually my blood pressure drops so low that I feel like I'm going to pass out, and there's nothing they can really do about it. So, after treatment is all finished I probably have to sit about half an hour to get to where I feel like I can walk, because I drive there myself…. So, basically after leaving I go home and go to bed."

Linda, who worked in-clinic, noticed that most of her patients, "are so wiped out from dialysis treatment" and she continued later that "they (the patients) just went home and would go to bed (after treatment)." The physical exhaustion was felt by Phillip who chalked up his in-clinic days to "I came straight home and went to bed (after treatment)," but now he has more "normal days" with at-home hemodialysis treatment. Sarah explained that her feelings of being "wore out" were due to the amount of fluid pulled off in-clinic, but that even with at-home dialysis she still takes her exhaustion feelings "day-by-day."

> **Sarah:** "In-center wore me out worse than in home. In-center I would lose the whole day, because I would be so wore out. I would be blessed to get home and I would just crawl to bed, and literally that's the way it would be. If I had a good run, I might get the half of the next day where I felt like a human being just so I could go back and do it the day after. It was crazy."

**Emotional Feelings as "This has been one huge roller coaster ride."**

As with most medical diagnoses, there is an initial shock, denial, and eventually acceptance. Phillip described his initial reaction as a "shock," even though his family had a history of kidney failure and dialysis. Ashley "didn't expect to be on dialysis," and later explained that "(I) didn't think I could do dialysis." A "roller coaster of emotions" was continually used by the participants, but was best described by Lauren, who explained her highs and lows as she went through this life altering event.

> **Lauren:** "Honestly, this has been one huge roller coaster ride. When I was first diagnosed, I was in a very low place. My entire life had changed. I was a very independent woman who lived on my own, worked a full-time job, and was really happy at where I was in my life. Then in what seemed like a blink of an eye I could no longer

work, I had to move back in with my parents, and I was strapped to a dialysis machine for 4 hours three days a week."

**"I went through the grief process."** Patients on dialysis appear to go through a grief process. Some patients may go through this only once in the beginning, but for others the feeling may be recurring. Along with the grief process there is the omnipresent feelings of seclusion, depression, anxiety, and anti-social feelings. Ashley vividly described as a recurring feeling.

> **Ashley**: "I went through the grief process because it's like you lose that that life that you lived before treatment starts and I go through that periodically, I think everyone does the anger, the denial, and the depression and the whole bit.

Most participants described their bouts with depression and anxiety as a part of their life, even though they tried to be positive. Catherine explained that she had depression and anti-social feelings, but that "I do sometimes feel a little better on the days that I don't have it, (but) when I do know I'm going that day it makes me a little more anxious and it puts me in a worse mood." Carol, a 52-year-old caregiver, spoke about her late husband's feelings about dialysis.

> **Carol:** "He was just depressed with the whole dialysis situation. He was a go-getter kind of guy, and was always active. When we went places, everyone knew him. (He was a) pretty popular guy, and then he basically just chose to seclude after he got on dialysis."

**"I hate it with everything in me."** The need to go to dialysis, and carry on as "normal" as possible appears to be a struggle for all participants interviewed. Dialysis is not a choice, it is most bluntly the "only way to keep you alive," as Catherine described dialysis treatment. Jennifer explained that she often "get(s) really down and wonder why I'm doing it," and later she stated that "you know you do it because you want to keep living, so you just do it." Even though it is often described as "torture" by Sarah, dialysis patients continue and fight their daily battles. Sarah described the feeling as a "fight," and that you "fight every time" you go to treatment.

> **Sarah**: "I hate it with everything in me but I fight it every time I get on. I just fight. I fight every time I get on. You've got to do this or you won't be alive. You've got to do

> this. You just tell yourself that kind of stuff over and over to get through it. You argue with yourself, well you know, if you just stop doing dialysis people that love you, well you know 'how would you feel if someone you loved was on dialysis' and that's what you tell yourself… If I didn't have those people in my life, I probably wouldn't have ever started dialysis. I would have just said it's over I'm done… I feel frustrated probably the whole time I'm on. Isn't that sad? I shouldn't feel that way [laughter]. You gotta fight because people love you. It was an opportunity I guess it what I'm saying."

**"You can always find the good with the bad."** Even with the depression and not wanting to go to dialysis, most participants strived to have positive attitudes and strong motivations for continuing their difficult path. Rachel explained that she "(tries) to have a good attitude when I go in I don't try to think of it as the ad the machine is keeping me alive right now." She later mentioned that even though she feels more depressed she tries to "shake it off," and she does not want "to have a self-pity party… because there are always people that are worse off than you." Family, support systems, and religion were all motivating factors that aided the participants to strive forward. Lauren was thankful that she "was surrounded by an amazing support team who picked me up, and helped me accept the cards I was dealt." Ashley also credited her family to her positive attitude and motivation to keep going.

> **Ashley:** "I'm grateful for a great husband who is there for me and my kids. I try to have a really good attitude, and you can always find good with the bad you just have to look for it. That's really kept me going. That and having a great husband. We've been married almost 35 years. I feel really blessed."

## Challenges of Dialysis

Through an interpretative analysis of interview and in-clinic observation data, six theme categories arose for the challenges that dialysis patients face related to their clothing, which was the aim of research questions 1 and 2: to explore how the current design processes could be adapted to incorporate the user-orientated design process for mass customization of clothing for people on dialysis: (a) function vs. style as "What they call their dialysis uniform," (b) access site

as “It’s ugly. It looks like a big snake on your arm,” (c) blood pressure cuff as “You would probably have to disrobe that to put the cuff on,” (d) staining as “I try not to wear nice clothes there (clinic), because my clothes can get ruined,” (e) weight fluctuation as “(Dialysis) has really taken my body shape into strange places,” and (f) current design solutions as “They are butt ugly! I would never wear it out anywhere.” This theme category further determined user demands related to the user-oriented design process.

Within the access site theme category, three smaller themes developed that includes: (a) protection as “I had to be extra, extra careful,” (b) swelling as “It (the shirt) cut my circulation off like a homemade tourniquet,” and (c) concealment as “You don’t want people to know you are sick.” The current design solution theme category had two smaller themes emerge that included: adaptive design apparel as “All they did was adapt a regular tracksuit and stick a zipper in it” and self-customized apparel as “I went to a few tailors to see if they could make me something” or “Her sister made her outfits to wear to dialysis.” Each of these theme categories, begin to illicit design considerations for not only designing clothing for people on dialysis, but how mass customization of clothing can better fit their needs and wants.

**Function vs. Style as “What they call their dialysis uniform”**

In exploring what the particpants wore to dialysis and their daily lives, it became evident that there is a function over style priority for their wardrobes. “Comfort,” “ease of access,” “sweats,” and “gym clothes” were all used to describe participants dialysis outfits. Ashley stated that her preference for clothing was forced to change since starting dialysis, because “I have to access my arms and hands (often)… so I generally shop with that in mind.” Catherine described her wardrobe now as having “no style at all right now.”

> **Catherine**: “Well, I mean to be honest with you, before I was on dialysis I used to look for jeans and cute tops. Now I just want total comfort, and I put on some weight since the

> dialysis. So, I pretty much just live in yoga pants. You know anything that's made out of cotton stretchy and comfortable."

Some participants described their wardrobe as having "dialysis outfits" and day-to-day life outfits, but did not combine the two. Lauren explained that she had certain "100% for function" dialysis outfits that she would "interchange since I don't usually wear them in my day-to-day (life)." This approach of having specific clothing for dialysis was best described by Linda, who stated that her patients called their outfits a "dialysis uniform."

> **Linda:** "But you know they usually have what they call their dialysis uniform. They wear the same thing almost every time, and usually a lot of times it was sweat pants, comfy pants, very loose fitting clothes, t-shirts, things like that. Some would change and put on slippers for some reason, but I don't know what that's all about. Some of the younger ones might wear something different."

Some participants tried to dress "the way I was before and I found out quickly that was not going to work" as Sarah described it was more of a "hassle" to try to wear her "cute tops." Jennifer desperately wished that she could have a "normal shirt (that is) long sleeve," so she could "wear it and then just be able to run out the door when I'm done (with dialysis)." She, among many other participants, were frustrated that they would have to change before going anywhere before or after treatment. Most participants interviewed worked and/or have active daily lives, so the need to change appears to hinder them and their lives. Ashley called the process "a pain." She said that she always went home to change or would have "take a bag with me so I can change at the clinic," because she lived about 25 miles away from her clinic. Stacy also brought clothes to change into, because she went to work after and could not wear her "business casual" work outfits or "sweaters" during treatment.

> **Sarah:** "It sounds stupid, but if I could look nice during dialysis, you know when you look nice you always feel better, like when you get out the shower and get ready (for the day). It just builds your confidence, or maybe it's a comfort thing. I don't know."

The sacrifice for function over style, was more evident among the women than men participants, but there was a clear priority of comfort for both. The men in this study have at home treatment, so many of them had more freedom with their apparel choices that included wearing pajamas, button-up shirts, or no shirt at all. Henry on the other hand explained that he dressed for comfort, but bought his sweatpants at Nordstrom and other department stores to have better quality and style. Carol stated several times that her late husband was continually "frustrated" that he could not dress "nice," and that he "sacrificed function for style."

> **Carol:** "When he first started dialysis he would wear jeans and a long sleeve shirt with another shirt over it…He always tried to look nice, and I told him he was going to sit in a chair for 3 1/2 hours why don't you wear something more comfortable. And then he finally started wearing pajamas and sweatpants and then he was more comfortable… He would have loved to (have) went in his regular clothes and done dialysis, because he wasn't the kind of guy that wanted to wear pajamas. He didn't like it, but as he got worse off he ended up just wearing pajamas and slippers and more comfortable things. He wasn't really happy with it ever, but I told him to just be comfortable and don't worry about what others think about you."

Donning and doffing of apparel was also a functional issue for some participants. Mainly pullover tops and jackets, because of access sites. Linda said some of her older patients had "an issue having a pull over." Rachel, the only participant in a wheel chair, mentioned that she needed aid in dressing with certain clothing such as, bras and pull over tops. Ann described t-shirts and pull overs as "challenging" for her husband.

> **Ann:** "It was challenging for him sometimes he would try to pull off a t-shirt but it would get stuck on the chest catheter. Yeah I mean especially t-shirts were hard to get off and he had to be mindful of how he was going to get it off and over the shoulder area and especially things that were form fitting."

**Access Site as "It's ugly. It looks like a big snake on your arm."**

The location and type of access site for patients effects their clothing choices, not only for dialysis, but also for their day-to-day lives. There are challenges with the access site other

than location that include: (a) protection and (b) concelament. The access site locations ranged for participants, which included: upper and lower arm access (fistulas and grafts), groin catheters, chest catheters, and PD stomach catheters. All had separate but similar issues related to protection, concealment, and ease of access. The access site locations can be "exposing" and "embarrasing" for many participants. Ashley was continually embarrased when she had her groin catheter, because "I had to wear shorts and even the shorts had to be pulled up to the point where I was exposed and I had no privacy." Sarah described her upper arm access site as "ugly" and "frustrating."

> **Sarah:** "I like that it's (access site) hidden. If I wear t-shirts, I don't have to worry about wearing long sleeves all the time. (I dress) mainly for modesty. It's ugly. It looks like a big snake on your arm. It's ugly, and I have an aneurysm on mine. They did surgery twice and it didn't stop it. It's right above my elbow, and it looks like a pyramid coming out of my arm. Yeah, it's crazy. It's ugly. It's embarrassing."

Access sites must be exposed during treatment in case of bleed outs, but it can be difficult to wear proper clothing that has ease of access and meets patients' needs and wants. Many participants had issues with learning what to wear to access their sites in the beginning, such as Lauren who said when she began her dialysis treatments she wore a "regular shirt" with her chest catheter, which resulted in the nurses having to "cut the collar of the t-shirt (off)." When prompted about their access sites and clothing, most wished they could wear something that would keep them warm and have easier access. Especially Rachel, who bluntly stated "I wish I could have something that was nicer and have easier access." On the other hand, Henry refused to wear clothing that exposed him in-clinic, stating "a lot of our human rights get lost (on dialysis)," and he did not want to sacrifice his "independence and respect and dignity" with wearing items that exposed him for easier access. Most participants with upper arm access sites cannot wear long sleeve shirts, because "you have to have your whole arm exposed" as Ashley

explained. Andrea noted that she must have her arm "exposed" at clinic, because they are not allowed to cover it up.

> **Andrea:** "It doesn't matter you are cold. You have to wear a short sleeve, because you have to have your arm exposed. I always knew that I had to wear a t-shirt. That was my only option, and I knew that."

**Protection as "I had to be extra, extra careful."** Protection of the access site is of the upmost importance for dialysis patients. Most participants had "lost" at least one site location in the past for various reasons, so they were adamant to keep their current access sites. Linda mentioned that since her husband liked to be outside and work in his woodshop, he needed a long sleeve shirt and bandages to protect his arm "when he wants to do something that is dirty work." Aneurysms on fistulas, which Henry described as "(the veins) balloon up and can burst," are an issue for many patients with these type of access sites. Patients, such as Patrick, a 36-year-old dialysis patient, has "lumps on my arm," so he must "wear long sleeve shirts and can't wear a watch on my arm anymore." He went on to explain that he has be careful picking up items, and not let his arm get hit. Sarah described her access site situation in a similar manner.

> **Sarah:** "I can't lift over 20lbs with that arm. It's not very much. I've actually had people go to grab me by the arm and have to catch it. I don't think it would be bad if someone did, but I don't want them to feel that (my fistula). My fistula has had so many issues with aneurysms and stuff I don't want anyone to touch it. I don't want it touched until it needs to be used, because I don't want another one. It makes me feel like I'm being rude, because I'll jerk myself away if I see someone trying to do that. I try to avoid it, if at all possible, because then you have to explain yourself. You don't want that person to think that you're being rude to them, because you don't mean it that way."

Catheters, in any location, need as much, if not more, precaution and protection to keep the risk of infection or damaging the catheter low. David stated that his issue with his PD catheter was making sure it did not "(fall) out of the bottom" of his shorts, and making sure there was slack for catheter when he taped it up on his body, so it would not catch on anything. Carol

reiterated that her husband would have to keep a patch over his PD catheter for protection, but that it was "uncomfortable for him to wear jeans" with it. Ann said that her late husband had issues with keeping gauze and tape on his central line, chest catheter, and that it made him "uncomfortable." She later mentioned that something as simple as "seat belts" and clothing "pushed right against it," which "concerned" and worried him. Ashley explained that her groin catheter needed extra care, because it would catch on clothing and fall easily.

> **Ashley:** "Yeah, (I) had to wear shorts in the winter, and then I had to be extra, extra careful with the groin catheter. It's because of infection risk or catching it on something. I mean it had to be taped down and it would catch on clothes. (It was the) same with the chest catheter…I had to keep them taped down. The one on my leg dangled down and it would catch on things, so I had to tape it. When you use the bathroom, it dangles so you got to make sure it stays clean and protected. Same with chest catheter they prefer that the end of those are covered and usually wrap them in gauze and tape them, and it would always get caught in my bra."

**Swelling as "It (the shirt) cut my circulation off like a homemade tourniquet"**

Swelling of the access sites, mainly fistulas, were found to be another significant issue that can alter clothing purchases for patients. Participants expressed concern focused on "loose" clothing and not wearing anything "tight" around their arms. Some participants, such as Phillip described his fistulas as "(it) sits up on my arm and sticks out." Later in his interview he mentioned that he often had dress shirts tailored because of his access site swelling. Sarah also noted that her fistula "gets bigger" and made her arms look "uneven," which made her feel self-conscious but "vain."

> **Sarah: "**My fistula rose and it gets bigger, and the sleeve gets tighter. I need a minimal width on my sleeves… because I don't want my arms to look uneven. I don't want the left arm to look uneven. Isn't that terrible? I sound so vein, but I don't want my left arm to look tight in that sleeve and the right arm to be hanging loose. Because it will bring attention to it (her access site arm). It's just me, but to me it would bring attention to my arm."

Andrea explained that she had purchased clothing that was too tight and she could "see a bump from my fistula through my sleeve," which she described as aesthetically unappealing and physically uncomfortable with her upper arm fistula. She said now she prefers "stretchy" fabrics that do not constrict her arms. Patrick expressed a similar issue of not being able to wear fitted, tight dress shirts because of his forearm fistula. Rachel desperately wished that she could purchase longer sleeve clothing that would not constrict her arm, so much so, that she suggested a top with snaps to possibly solve her problem.

> **Rachel:** "I would like to wear a longer sleeve though. It wouldn't even have to be a full sleeve, but even just to the elbow or something. Something I could even unsnap, so I don't have to roll it up and have it cut my circulation off like a homemade tourniquet [laughter]."

**Concealment as "You don't want people to know you are sick."** The ability to conceal the access site was a concern for most participants. Some participants, such as Sarah are thankful to have an upper arm access site, because they can easily hide their access site with a t-shirt and "not have to worry about wearing long sleeves all the time."

> **Sarah:** "When I'm out and about I don't want anyone to know. I don't know why we are this way. I think we may all be to a point, but you don't want people to know you are sick, or that you have a problem, (or) that you have a medical issue. You don't want to talk about it all the time, and when I'm away from it I want to be away from it. At this point, when I'm away from the house I don't want to think about it, and I don't want to talk about (it). I don't want anyone to approach me or ask me any questions."

The varying access site locations do not appear to alter participant's feelings on keeping the site concealed. Most participants did express feelings of remaining "modest," and attempting to "conceal" the access site from public view. Self-esteem and confidence, related to the access site's location and appearance, were factors of concern for most participants. Jennifer best explained her feelings of "embarrassment," and how she disliked when strangers gave her "pity."

> **Jennifer:** "I don't wear tank tops anymore, because I do have a bulging fistula…It's just what it is, but I do like keeping it covered. You know, I don't like answering all the

> questions... ‘What's that?’ ‘How come that's there?’ ‘What is it?’ I'm just like okay, ‘you know what’ go away. If I don't know you, I don't really want to discuss it. They (strangers) are very bold and very gutsy, and it's like really? You know once, I had just gotten done (at dialysis), and I had gauze on my arm. I had gone shopping, and they (the employees) were all ‘Oh no, what happened to your arm?!’ I was thinking ‘Really?!... please go away.’ I just pulled on my shirt to try to pull it down, and just ignored the questions. It's like I don't really want to get intimate with the explanation of that I have renal failure (and) I'm on dialysis, because that ends up asking a hell of a lot more questions. Then you get the ‘Oh, I'm so sorry!’ And I'm thinking no you’re not. I mean I don't, don't, don't (…) I don't want your sympathy, because I don't even give myself sympathy. It is what it is.”

The self-conscious feelings about their access site influenced most participants clothing choices. Andrea said that she “only purchase(s) t-shirts that sells elbow length,” because she likes to cover her fistula and “I don’t particularity want people looking at it.” Almost all the women participants, with upper arm access sites, reiterated the same comment of only shopping for “elbow length,” “3/4 length,” or “full sleeve.” Participants with PD catheters and chest and groin catheters, expressed similar feelings of not wanting the catheters “exposed,” and that they tried to “hide” them under clothing. Catherine explained that she would “wrap (the catheter) up and tape it” to her skin, and that she “couldn’t wear any clothes that were tight fitting because you could see through it.” Phillip stated “that (people seeing his access site) doesn’t really bother” him, but others such as Patrick “I needed longer shirts to hide (the catheter), and Ann’s late husband were all adamant about concealing it.

> **Ann:** “Even for the chest catheter, if he were to wear a t- shirt you would be able to see the outline of it in a thin t-shirt. He would want to cover up a little bit, so people wouldn't wonder what that was under his shirt. I think it was a self-esteem thing… (He had other) medical issues and different kinds of things on his body (that) made him not want to show it…You know he just wanted to not have anything that would stick out. He just wanted to be a normal person as much as he could, so he tried to minimize you know the other things that were going on that would try to make him stick out more I guess.”

**Blood Pressure Cuff as “You would probably have to disrobe to put the cuff on”**

The blood pressure cuff issue was discovered during the interpretative analysis of all interview data. The main issue is that one arm has the access site and the other has a blood pressure cuff on for the duration of the treatment, which leads to the inability of wearing thick materials with long sleeves and limited mobility during treatment. Ashley said that she "always wear(s) a short sleeve shirt (to clinic)," because "they (her clinic) really frowns on long sleeve shirts because they need to access for blood pressure." She continued on to say that most clinics she had patronized did not like "going over a shirt," because "they can't get the blood pressure (acurate reading)." Stacy expressed her annoyance with the cuff, "it (the blood pressure cuff) would destroy my sweaters…(from) the Velcro" when the clinic nurses tried to place the cuff over her sweaters. Catherine also mentioned that "I want to wear a hoodie or sweatshirt but it's too thick to (put) the blood pressure (cuff) thing around," so she had to take them off and "freeze" during treatmtent.

> **Linda:** "My husband uses a wrist cuff, because both his arms have fistulas, which is rare. But yes, it is an issue because you usually put it on the opposite arm, and if you have a long sleeve shirt it could cause it an issue. And then you are cold… The blood pressure cuff is attached to their (the patient's) machine, so it reads on their (the patient's) machine. It automatically inflates here and there, but sometimes if the material is too thick it won't take a proper reading. Like (if) someone came in with a heavy sweatshirt, you would probably have to disrobe that to put the cuff on."

**Staining as "I try not to wear nice clothes there (clinic), because my clothes can get ruined"**

Staining, whether from cleaning solutions or bleed outs, are almost guaranteed to happen at some point for a dialysis patient, especially if they have a fistula. Ann explained her late husband never wanted to wear anything nice during treatment, because they used heavy duty cleaners with his catheter, which caused bleach like stains. Many participants noted that they tended to wear "black," "gray," and other dark, "depressing" colors to hide any possible staining.

Sarah said she had issues with bleed outs in the past from her access site, and had learned to only "wear black or navy blue" for dialysis treatment.

> **Sarah:** "I quickly learned to wear black or navy blue, and that's all you will see me in on dialysis days… I mean truly I think that affects your mood, a lot of people, and a lot of people in my center (…) we just all stuck to black and navy blue that wouldn't show… It (dark shirts) doesn't show the blood."

Most participants tried to keep all their clothing in good condition, and they did not want it "ruined" from staining issues. Patrick mentioned that staining was one of his main issues with dialysis. Even patients that had never had a "bleed out," explained that they wore cheap clothing, dark colors, or clothing they did not care about just in case a bleed out happened. Ashley noted that she had several "bleeding issue that (blood) went through the dressing and onto (her) clothing." Rachel was the only participant that gave a detailed story of an extreme bleed out. She described the experience as "awful," and said she refused to wear nice clothing to her treatments now.

> **Rachel:** "I try not to wear nice clothes there, because my clothes can get ruined. It (the access site) doesn't always clot and blood runs down everywhere. One time I went to leave and got up and the sleeve of my jacket was hanging down (soaked with blood), so they quickly took me back to the chair. But it was so bad (that) it (the blood) went through my shirt, sweater, and jacket. It even got on my pants. So, they had to give a nurse gown to wear out, and I had to throw my clothes out. So, now they have started putting a clamp on my arm."

**Weight Fluctuation as "(Dialysis) has really taken my body shape into strange places"**

Several participants expressed an issue with weight fluctuation from dialysis mainly due to fluid retention, medications, stomach swelling from PD dialysis. Most participants expressed clothing issues related to stomach swelling and allover fluid retention. Stacy said she had "an odd shape," which she described as a having a stomach but not heavy on her legs or arms. It was an issue for her to find pants, especially jeans, that fit properly, so she mainly wore "a lot of

leggings" and some "skinny jeans." Henry, although a male, expressed a similar concern that "it's very hard to find a pair of jeans," which he described as "problematic." He also noted that he was unable to wear button-up shirts, and that he purchased a "winter coat from Nordstrom… (that is) fitted so I have to wear it open."

> **Henry:** "It's hard for me to find clothing properly because of the kidney transplant and the steroids I'm on. It has really taken my body shape into strange places. The prednisone has caused fluid retention, so my abdomen has gotten more enlarged and it has taken muscle mass away from me. My legs look like matchsticks to my eyes."

Peritoneal dialysis patients described their weight fluctuation issues as being "bloated" and that their weight was constantly "up and down." Linda verified that she had often observed PD patients that were "very bloated," because of their daily treatment "most of their stomachs get bloated up so their clothing does get tight." Carol verified that her late husband's "stomach would swell," and that he preferred loose clothing that did not "restrict" him. She continued later saying she saw his "body fluctuate in weight with dialysis," and she knew "when he lost weight because his ring would spin on his hands but within 24 hours they wouldn't spin anymore." This was due to the constant changes in fluid retention from dialysis treatments.

> **David:** "With PD your kind of bloated all the time. You know, I wouldn't want it (clothing) to be hugging me and feel the curves of the tube, just something that flows comfortably… Really with dialysis, your weight is pretty up and down. And they (doctors) are constantly changing your dose, and sometimes you retain water depending on your diet and fluid, more or less. So, it was probably the skinniest I've been, but it (my weight) could also go up and down several pounds. Or (I will) feel more bloated and retaining more water than usual, and (it) takes a while to get it off. Even post-transplant with all the medicines and everything, (it) has caused me to gain weight and be more bloated… I feel like I'm more in between in sizes now. A medium is too tight, but a large is too long. It's kind of like having a beer belly."

### Current Design Solutions as "They are butt ugly! I would never wear it out anywhere."

Current design solutions for dialysis patients include: (a) adaptive apparel that is mass produced specifically for dialysis patients, and (b) any self-customized or adapted apparel that

patients have altered themselves and/or have had professionally altered. This theme category has discovered that many participants were aware of current dialysis clothing available, and a few had purchased specific items. On the other hand, almost all participants had thought of having apparel altered or created to better meet their needs, had altered an item, or at least knew someone that had altered or created apparel. While these are basic solutions for dialysis patients, most participants seemed less than thrilled with the current available apparel. Self-customizations appeared to either not work for the participants, or be too expensive to have an item professionally tailor-made to meet their needs. Jennifer, an owner of an adapted dialysis patient sweatshirt, vividly described her opinions on owning two "dialysis sweatshirts."

> **Jennifer: "**It's (the dialysis adaptive clothing) an ugly brown sweatshirt. The other one is an ugly green sweatshirt. But they are comfortable and they keep me warm… Overall, they are comfortable, they keep me warm, but they are butt ugly! I would never wear it out anywhere. I get done dialyzing, and I take it off. (I) never (wear it) out. They are all unisex, so there's not one for women and one for men. It's all the same. So, it's like you order a medium and they are huge, because it's got to fit a medium man too… They are just butt ugly and they only come in dark colors… If I have that sweatshirt on, even my kids ask if I'm going to take it off before we go somewhere. It's just really bad."

**Adaptive Design Apparel as "All they did was adapt a regular tracksuit and stick a zipper in it."** Out of fifteen participants, eleven were aware that "dialysis clothing" existed in some form, but only four had purchased an item to try out. Among the participants that were aware of this type of apparel, there was a universal response of the apparel being "too expensive" and "not attractive." Ashley described "Ronwear" as "it looks nice but I don't like the zippers." She continued later in the interview bluntly expressing that the apparel "makes you look abnormal [laughter]," and "who has zippers on their upper arm it doesn't look great." Andrea, like other participants, explained her opinion on the apparel as "good for dialysis," but she "wouldn't want to wear it out." Linda, as an in-clinic worker, had concerns over the ability of the openings on the apparel to "really open it up enough" to access all sites easily. She did remember

one man that wore a pullover navy blue jacket with multiple access openings, but she did voice her concern that "having a pullover" could be an issue for some patients.

> **Stacy:** "I've seen stuff online with the openings and zippers for the arms and things like that, and that would be good for access but I need help with blood pressure… You would still have to push up the sleeve, so that doesn't help me much… I thought they were crazy expensive. It looks like all they did was adapt a regular tracksuit and stick a zipper in it. It's not like they did anything special design wise… I'm not the kind of person that's going to go out and buy a tracksuit. You know, whether I need it or not, that's not something I would buy."

Ann and Jennifer were the only two participants that had gotten dialysis jacket apparel. Jennifer's description above was blunt and truthful, she described the clothing as "ugly," but that she did like that "with both arms having zipper (access)" she could use her blood pressure cuff and keep her long sleeves. She also enjoyed the ability to zip the openings back up to enclose her arms, instead of them being "exposed." Ann described her late husband's zip-up dialysis jacket as "fleece" with "zippers on the arms and clavicle area so you could access (multiple areas)," was nice but "it was kind of just a sweat suit."

> **Ann:** "I thought it was really nice, but it is kind of just a sweat suit. It's for being comfortable. It's good, but you know you can't just sit around wearing sweats all the time…I mean I like the general idea of the jacket that he had, and I liked that he could zip it up and only have a little bit of exposed area. So, I mean I wish it was just a little better with where things are actually placed. It was meant for dialysis patients, but it was also general, which could be for chemotherapy or other treatments. So maybe if things were placed differently and faced the anatomy of where a chest catheter, and I know many don't have a chest catheter most have a fistula, but that might work out a little better."

Patrick and Catherine were the only participants that had the PD belts to aid with holding and protecting the stomach catheter. Other participants that had thought about purchasing a belt backed out because they thought they looked "bulky" and "expensive." David expressed his concern with not being able to "keep it clean," because the belts could raise infection risk with the catheter. Catherine described the belt as "big, thick elastic kind of belt that was very

uncomfortable," which resulted in the belt being seen under clothing. She did say that she liked the "belt hooks where you could feed the catheter through and it would go around your waist," but that it was too uncomfortable of a material. She also mentioned a "camisole top that had a pocket inside" to stick the catheter into, but she never purchased it because she wanted a "regular shirt" not something to wear underneath her clothing. Patrick described his belt as "expensive" and "designed poorly."

> **Patrick:** "I couldn't find tape that would stay (on my skin) the entire day, but then I found a website that sold belts that had a pouch on it that you could put the tubing in… That actually that kind of sucked…They're really expensive, don't work well, and was designed poorly… The pouch, that you would put the tubing into, was small, so it would kind of pinch (the catheter). So, it (the catheter) would bend over and come back, so if there is a pinch it can break the catheter. If the pouch was wider, it would have helped. The Velcro wouldn't lineup right, so it would hit you. I wish it was a snap."

**Self-Customized Apparel as "Nobody wants to take a perfectly good shirt and cut it up."** Self-customized apparel, for this research, is any item that a patient either created or adapted themselves or had someone else create for them to better meet their dialysis needs. After analysis of the interview data, most participants have known someone that has adapted an item to meet their needs, customized an item themselves, or have had an item professionally created for them. It is assumed that participants that did not customize an item themselves thought it was too much work, too expensive, did not want to cut up their clothing, and/or did not think about customizing an item.

> **Ashley:** "You know, I've been known to take a or buy a long sleeve shirt and cut one sleeves off… Yeah, just so I could stay warm, but you know nobody wants to take a perfectly good shirt and cut it up I've known several people that have done that."

Participants that had observed other patients with personal-customizations noted simple solutions that includes: slits in sleeves, cutting sleeves off, and slits in neckline. Sarah said she became so "desperate" to stay warm she "cut the left arm off" a long john top to layer under her

t-shirt, but that the nurses frowned on the layering because it added onto her "true dry weight." She explained that the dry weight needs to remain accurate, so the nurses know how much fluid to pull off. Lauren and Sarah described more in-depth customizations that included the use of Velcro and zippers. Lauren noted that a patient with a groin catheter sewed a "zipper on the inner thigh of her pants." Sarah described a patient in-clinic that wore a sweatshirt with "Velcro in it (the arm)," but that it was obvious that "something was going on." She said she would not want to wear something so obvious out in public. Linda vividly described a "dialysis outfit" that a patient's sister created for her that helped her greatly.

> **Linda:** "I did have one lady, that her sister made her outfits to wear to dialysis. Basically, they were jumpsuits with a culotte style, wide legs. So, if you were going to have to do a thigh graft, it could be done by just pulling it up like a skirt. They were very good. She made a nice rounded neckline in case there was a catheter. It was a one-piece outfit, but the legs were wide. They were pants that only came to her knees. It looked aesthetically pleasing with flower prints and other prints. You did notice it was a different style, but it was cute. The sleeves were kind of floppy, they weren't long sleeves, but they were kind of floppy so that you could roll them up. Kind of like a cap sleeve type style."

Several participants mentioned in their interviews that at some point they had considered having an item either created or tailored to better meet their needs, but none of them had the apparel created. Patrick noted that he went to "a few tailors to see if they could me something," but that they all "wanted over $90." He did not think the price was worth the solution. Phillip also mentioned that he went to a few professionals "to make me a sweatshirt with a little slit with a flap opening," which he described as a "pocket." He decided not to pursue it, because he went to at-home hemodialysis and did not think the price was worth it either. He did explain later in the interview that he paid expensive prices to have his dress shirts and suits "custom made" and "tailored," mainly due to his access site arm swelling.

## Design of Clothing

While the Challenges of Dialysis section focuses on dialysis patient's "needs" in term of apparel, this theme category focuses on dialysis patient's "wants" in terms of apparel by prioritizing their user demands. This section then explores research question 3: to apply the user-oriented design process for mass-customization to the clothing needs and wants of people on dialysis and create suggested clothing products and product distribution channel for this target market. After an analysis of interview data and their "wants" as related to their user-situation and needs four theme categories emerged: (a) fit as "We are all built differently but some clothing makers don't think about that," (b) fabrication as "I don't like anything that makes me itch," (c) colors as "Truly, I think that colors affect your mood," (d) style as "I have to really hunt for what I want."

**Fit as "We are all built differently but some clothing makers don't think about that."**

For theme 1, fit, as a "want" for dialysis patients, was a unanimous response of "loose" and "flowy." No participant said they wanted "tight" or "clingy" apparel, although some participants, such as Jennifer explained she looked for a "looser, normal fit" but not "oversized." David expressed a similar opinion of "not (wanting) a tight t-shirt but not too baggy either." The importance of having apparel that has a loose fit was mainly because the patients sit for so long at dialysis, weight fluctuation and access site swelling, and/or for concealment and modesty concerns. Lauren mentioned that she liked "men's shirts," because they are "bigger" and "more comfortable when lying in a chair for four hours."

Weight fluctuation was a main concern for fit of clothing. Many participants explained that if their fluid retention changed or their access site swelled, they needed clothing that would continue to fit them well. Carol only purchased "big shirts" but more fitted pants, because her

late husband wanted to look “nice” but he needed room for swelling of his PD stomach area. Several participants were petite, but also experienced weight fluctuation due to dialysis, so their struggle with fit was more pertinent. Andrea revealed that her body type was “not plus size but short and wide,” so a lot “is too big.” She continued to say that “things don’t always come proportioned for me,” which resulted in her thinking that “things are not fashioned for short they are fashioned for people that are tall.” Her frustration and wishes for better fitting apparel, was also felt by Rachel who had a similar body shape and thoughts about the fashion industry.

> **Rachel:** “I like looser fitting clothing… I'm also petite, so sometimes it's difficult. Yeah, because if you get petite, even though I'm a size large, I have a long torso, so the arms may be too long but it won't right in the torso. It may be too baggy in certain areas where I'm smaller like the back and my thighs and legs. They don't think of big people being smaller and shorter. We are all built differently, but some clothing makers don't think about that. I don't like to purchase clothing that makes me look like an older woman, but being shorter I can't buy certain things and styles. Now my style is changing though, because I'm in a wheelchair. So, I have to figure out what looks good sitting in a wheelchair.”

Several participants expressed concerns of fit related to their access site swelling and the ability to keep the site concealed. Phillip continually noted that he preferred apparel that was “loose on your arm so you don’t feel restricted with it (access site).” He later explained that it was often difficult to find men’s apparel that fit his access site swelling needs. Ann mentioned that her late husband did not want his chest catheter seen, so he would wear “baggy” clothing but that it was difficult to “cover up” without layering. Catherine had a similar frustration with her site being “more difficult to conceal” with her apparel, so she did not wear clothes that were “tight fitting because you could see (the access site).” Sarah mentioned throughout her interview the importance of having nice, comfortable clothing for dialysis, but also the ability to conceal her access site so it doesn’t “bring attention to it.”

> **Sarah:** “I don't like anything tight. (I like) loose (clothing). I pay close attention to the sleeves. Because if it's a tighter sleeve, then it's going to be harder for me to roll it up

> over my shoulder. But if it's just the right looseness it's easier, and I don't have as much of a problem with it… I've got to try it on to make sure it's going to fit, because my fistula rose and it gets bigger and the sleeve gets tighter and I need a minimal width on my sleeves."

**Fabrication as "I don't like anything that makes me itch"**

The second theme of "wants" for dialysis patients apparel was fabrication. Fabrication had three elements of soft, stretchy fabrics that are wrinkle-resistant, fabrics that keep patients warm, and fabric that is long-lasting, i.e. "washes well." In a similar fashion as fit, the number one factor for fabrication was "comfort." Patrick described his ideal dialysis and daily life outfit as a "button up shirt that's more comfortable to wear," because his current ones are not "soft like you want, like cotton, they more like a dress shirt material;" He described it as almost a "button up t-shirt." Andrea explained that she preferred "cotton" and fabrics that "don't cling," and that she shopped for comfort now "it doesn't matter what it look likes" if "I was uncomfortable I wouldn't buy (it)." Stacy, like other patients, was adamant that she wanted comfortable and soft materials that were wrinkle-resistant, because she sits for long periods of time at dialysis and at work.

> **Stacy:** "I didn't like anything (clothing) that makes me itch, so I was looking for softer fabrics. A lot of cotton things like that… Well, you know, I tried to not wear pants that would wrinkle badly, because you have to sit in the chair so long almost 4 hours. So, I would try to wear mostly leggings, so that way it was comfortable and once I put a sweater on or a jacket it looked decent with boots or something."

All participants indicated that keeping warm in-clinic is a top priority, and most wanted a fabric that was not only comfortable, but that would keep them warm. Phillip described his ideal dialysis outfit as "thermal (and) something that would keep you warm, especially in-clinic," and clothing that would "keep your body heat in and (keep you) warm." Sarah wished more fabrics

were available to her that would "keep you cool in the summer and cozy in the winter." Rachel also expressed a "want" for clothes that were warm but that would also "breathe."

Long-lasting and easy to care for clothing was also a factor for fabrication. Patients need clothing that will last through several washes and staining treatments. Jennifer wanted her clothing to continually look "nice," so having good quality fabrics that wash well are important. Rose insisted on not purchasing clothing that "would have to be dry cleaned or ironed." Ashley insisted on having clothing that is easy to wash and can hold up to her treating stains often. Staining of fabrics is an issue for many patients on dialysis, so the ability to have stain-resistant or resilient fabric is a "want" for patients.

> **Ashley:** "Um… how it well it washes. Because, I mean, if you know I do get blood on my clothes and it happens, I want to be able to treat it and wash it and it will still look clean and it's the same. And (I want to) make sure it washes it (the clothing) and gets the stain out and it still looks, you know, I want it to stay clean and crisp."

**Colors as "Truly, I think that colors affect your mood."**

The third theme is colors and patterns of apparel, and the "want" is to have more "cheerful" colors and not feeling the need to wear dark colors all the time. A similar "want" among participants was to have more color options. Ashley expressed frustration with her color choice "I like softer colors, not big and bold and it does make my choices limited." She continued saying that "it's hard to find (colorful clothing)." Jennifer wished that her "dialysis sweatshirts" were available in bright colors and even lighter, pastels but they only came in dark colors "probably because of the staining and blood stains that can happen." Most patients purchase of only "dark colors" was due to staining issues. There appears to be a "want" of stain resistant clothing that is available in more "cheerful" color schemes and patterns. Sarah explained that she, and most others in her clinic, wore only dark colors, but it was depressing and affected their mood.

> **Sarah:** "I wouldn't want my tops to be dark, naturally. I like light colors, like robin's egg blue or light teal, mint, peachy colors, (like) pastels. I even enjoy gray, gray doesn't depress me. I know it does a lot of people, but I even enjoy gray with white, stuff like that… I mean truly I think that colors affect your mood. A lot of people, and a lot of people in my center, we're like we just all stuck to black and navy blue that wouldn't show."

**Style as "I have to really hunt for what I want."**

The fourth theme is the overall "style" that participants wanted to wear. This theme includes expressions of frustrations with current apparel, overall style "wants" for apparel, and closure options that participants prefer. The struggle and frustration to shop for apparel that worked for paritcipants needs and wants was all to obvious when analyzing the interview data. As previously stated, patients scarifice function for style, but they aspire for more style in their wardrobe. Ashley expressed feelings of frustration trying to shop for modest and concealing clothing that fit "what I want and what I need."

> **Ashley: "**So, sometimes it's harder to find (sleeve) styles that have different lengths. I like capris too and they are coming back. I am a modest dresser in that sense. (I like) loose and flowy. I don't really like long sleeves that much, so that gives me a disadvantage… I have to really hunt for what I want and what I need. It takes a lot of effort to find the sleeves and the neckline and the colors and what not that fits my criteria. It's not really enjoyable. I hate to say I never thought I was never really picky, but I have the become that way because of the dialysis."

The overall "want" for style that participants expressed was to be able to wear their day-to-day clothing to dialysis without needing to change before or after treatment. Phillip expressed that he wanted dialysis clothing that had "some kind of style to it." Even though Jennifer has her treatments at-home, she still shared the frustration of wanting to "be able to wear (something) and then just be able to run out the door when I'm done (with treatment)." The ability to seamlessly have clothing that meets day-to-day life and dialysis treatment needs and wants is apparent for in-clinic and at-home dialysis patients. Sarah admitted that she wished she had

"nicer" and more "stylish" clothing, because she thought it would boost her confidence and overall mood.

> **Sarah:** "It sounds stupid, but if I could look nice during dialysis, you know, when you look nice you always feel better. When you get out the shower and get ready (for the day), it just builds your confidence…I like, well kind of a mixed style, I like lace and crochet part tops, blousy romantic style that are boho style. Like a cross between romantic and boho… The only time I get to really enjoy it (stylish clothing) is when I'm out running errands, going to the doctor's office, or going to church. I don't get to enjoy it on a daily basis, because those days it's just a t-shirt all day… I really think it would boost our moods, you know we could all look pretty and nice."

Using interview data and the research designer's journal, data was analyzed to create garments to meet the patients' needs and wants. Most participants agreed that they liked the idea of the current dialysis clothing available, because of the access site options, but that they were not aesthetically pleasing to wear out in their daily lives and/or they looked too different from mainstream apparel. The need to not stand out and conceal their access sites was apparent throughout, and it carried over into their style wants. Andrea said that she did not "want to be walking around with something obvious that is for dialysis," but that she liked the ability to have ease of access. As far as closures for the access sites, most preferred something not obvious and hidden. Jennifer wished she could have apparel with access to both arms, because of the blood pressure cuff, but not be obvious that the access was there. Closures also goes along with dressing, which a few participants wished for easier ways to dress. Zip-up jackets and button-shirts were a few ways that participants said were easier for them to don and doff. Catherine noted that she did not like "buttons or zippers" on her pants, explaining that yoga pants and leggings were easier and more comfortable to wear.

## Design Solutions

The final theme category focused on the design solutions for the participants and answered research question 3. Following the user-oriented design process adapted from Rosenblad-Wallin (1985), after all data has been gathered from the user and analyzed into priorities, the designer then develops several ideas and possible solutions to create the best solution. Figure 5 shows the adapted user-oriented design process for this study. The user-oriented design process is discussed to show how it was adapted for this study. Rosenblad-Wallin's (1985) design process chose to focus on functional clothing, whereas this study is focusing on the functional and aesthetic needs and wants related to clothing. Rosenblad-Wallin (1985) included functional and symbolic values to determine clothing needs, while Lamb and Kallal (1992) modified past apparel design processes to include functional, expressive, and aesthetic values related to apparel for PLWD. While Rosenblad-Wallin's (1985) symbolic value includes a definition of fashionable and attractive clothing, he stated that the main principal of the value is how "clothing are found in the impression the wearer gives to people by his exterior appearance" (p. 280). The researcher felt that this principal was not enough to properly design clothing for dialysis patients, because more is needed than the exterior appearance in public. The users' need to feel and look good was determined to be for themselves, at dialysis, at home, and in public are important, not just solely on how others perceive them in public.

While symbolic values are an important factor of clothing, this research is suggesting there is more to the value than how the users are perceived by others and their emotions. This study is also suggesting that symbolic or expressive and aesthetic values do not need to be separated as Lamb and Kallal (1992) suggested, but that they can be combined because they are so interrelated. This research refers to symbolic values as "aesthetic values," meaning that not

only is the physical aesthetics of the garment concerned, but also the emotional and cultural expressions that go along with wearing clothing in public. This study's functional values and design solution ideas incorporate mass customization options. Mass customization options, along with the participants user-situations and demands and functional and aesthetic values, have been used to create an inspiration board, hand sketches, and one final prototype. Figure 6 shows the researcher's defined functional and aesthetic values.

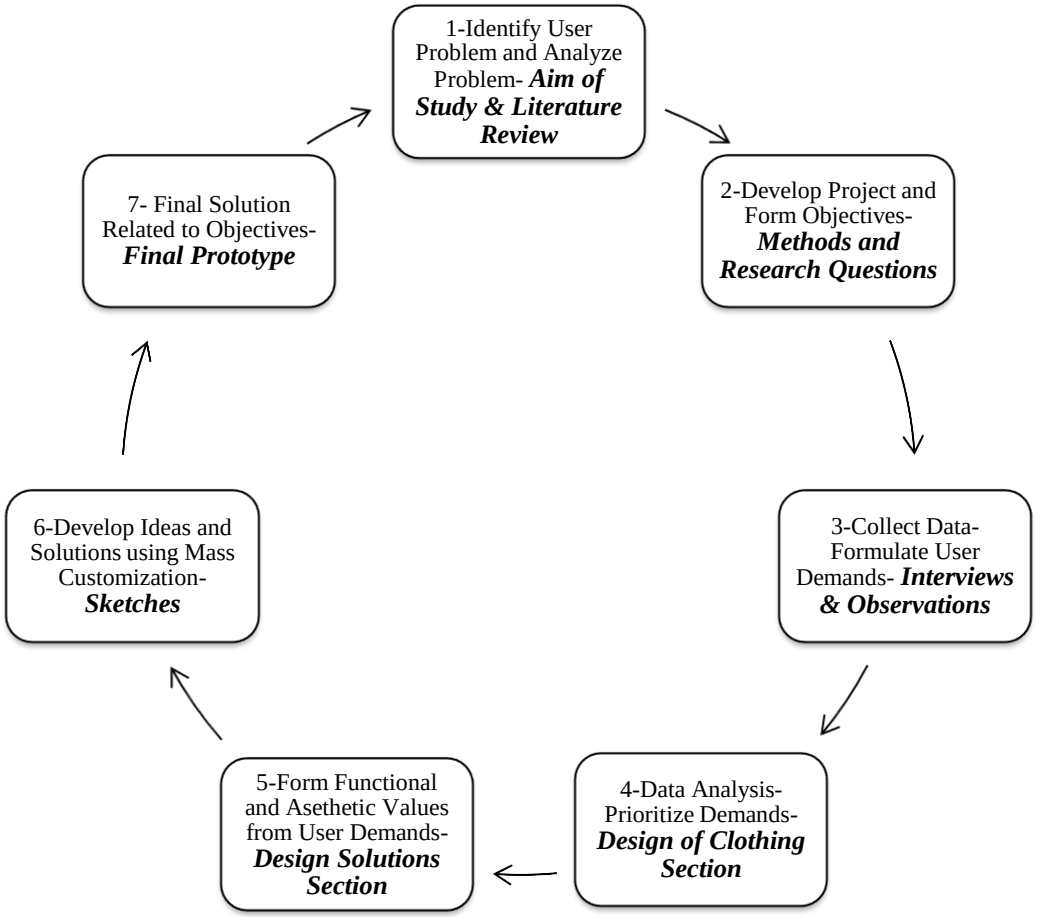


**Figure 5. Researcher's User-Oriented Design Process**

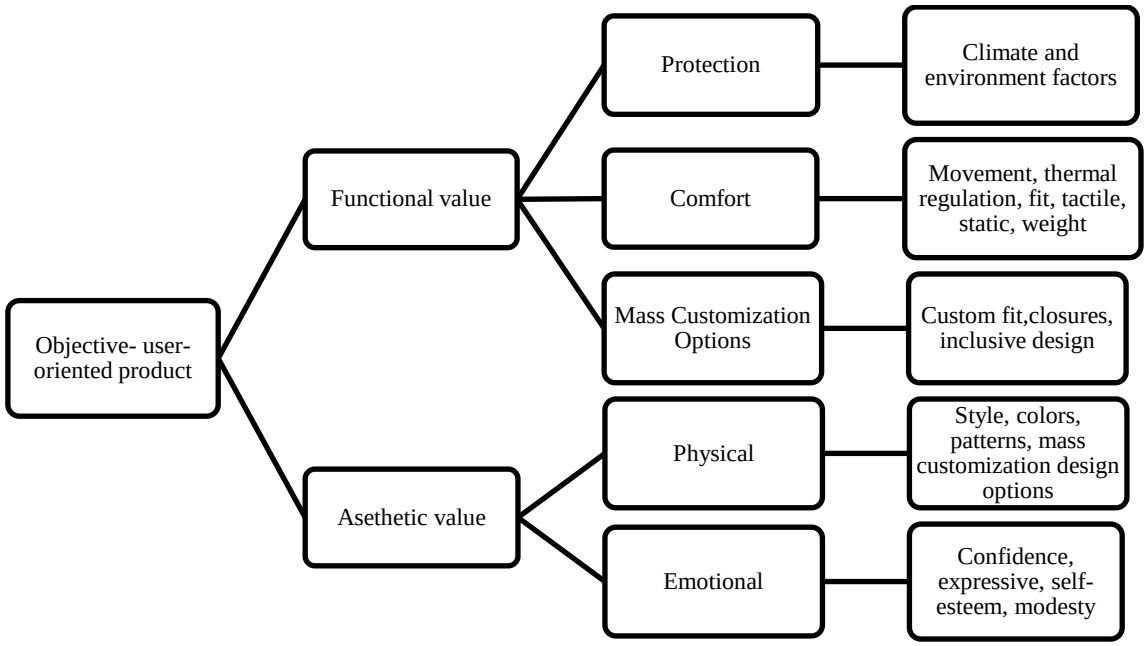


**Figure 6. Reseracher's Functioanl and Asethetic Values**

**User-Oriented Design Process**

The first three steps in the adapted user-oriented design process includes: identification of the user problem, analyze the problem, and then develop the project and set objectives. For this study, the purpose was to gain an understanding of dialysis patients' apparel needs and wants and apply those needs and wants to design and develop clothing that can be mass customized and used as inclusive apparel for all. A thorough literature review was conducted to complete the analysis of the problem to have a set of predetermined values as Rosenblad-Wallin (1985) suggested. The formulation of the project and the data collection process included conducting one-on-one in-depth interviews, conduct observations in the sample's environments, and design potential solutions for this target market. After conducting 15 interviews and observing the participants and clinic environments, the designer better understands the demands and use-situation of the participants of this study. The objectives became the research questions, which includes:

1. To understand how the traditional design process and mass apparel production are failing to meet the clothing needs and wants of PLWD, specifically for people on dialysis.

2. To explore how the current design processes could be adapted to incorporate the user-orientated design process for mass customization of clothing for people on dialysis.

3. To apply the user-oriented design process for mass-customization to the clothing needs and wants of people on dialysis and create suggested clothing products and product distribution channel for this target market.

**Data analysis.** The fourth step, data analysis and prioritization of user demands, is the detailed Design of Clothing section in the theme categories. Data collected from the interviews were transcribed and then analyzed by breaking apart and putting back together individual transcriptions, and conducting the same process with the transcriptions as a whole. This allowed for themes to emerge organically from the data and individual sub-themes to emerge after the initial themes were created to better inform design solutions. The user demands were developed from the data collected and were prioritized based off of the participant's needs and wants related to their use-situation. These included the fit, fabrication, colors, and overall style wants and needs.

**Form Functional and Aesthetic Values.** The fifth step in the process is to formulate the functional and aesthetic values from the user demands and situations. These values allow the designs created to be both functional and aesthetically pleasing for the user and their demands. The user-demands and use-situation data that was analyzed is now specified into functional and aesthetic values to allow for the best design solutions possible. These values should be able to create clothing that can take dialysis patients from treatment, whether at-home or in-clinic, to their day-to-day activities without needing to change.

***Functional values.*** Rosenblad-Wallin (1985) separated functional values into the essential parts of a garment that everyone needs, which includes: protection, ie. survival and

security from the elements and environment, and comfort, i.e. thermal regulation, ease of movement, fit, weight, friction, and tactility. Mass customization design options are also included in the functionality of the apparel. For this study, fit, fabrics, protection, and finishes were specified as functional values.

*"I don't like anything tight."* User demands were prioritized for the fit of clothing, and it was found that most participants preferred loose, flowy clothing. Andrea, among most other patients, said she had "issues with fit," and that she did not like "clingy clothes" and "I don't like anything tight." Clothing should be designed with various body shapes in mind including plus size and petite. Dialysis patients have access site swelling and weight fluctuation, so clothing should be loose enough to conceal these body imperfections and continue to fit during fluctuations. Clothing should not be sloppy and baggy because it will become cumbersome.

*"To me, comfort is number one priority."* In-order to meet user's functional values, the fabric of the clothing should be soft, light, and stretchy so that patients have the continued comfort level they want and need. Lauren expressed her need for comfort as a "number one priority." Cotton and knits appear to be a good option for most users, but the fabric needs have enough stretch so they can roll sleeves up, and have a well-fitted garment. The fabrics should not take up a lot of space or add a lot of extra weight to the wearer. The fabrics should also be wrinkle-resistant, due to the fact that dialysis patients must sit for long periods of time. They want clothing that can take them from treatment to their day-to-day activities, so they do not want wrinkled clothing. They also need clothing that is stain-resistant, so the use of darker fabrics that are stain resistant are of value. Dialysis patients also need to keep warm during treatment, whether at-home or in-clinic, so the fabric should insulate well. The use of smart textiles for stain-resilience and thermal regulation clothing is an option to solve this problem.

*"They have to protect it, and not let bad germs get at it."* Dialysis patients need to keep their access sites clean and protected, especially when out in public and working outside. They need to keep their access sites clean, and hidden to lower infection risk. Most participants emphasized that they did not like other people to see or touch their access sites, and many feared foreign objects hitting it when performing activities, such as working outside or in a wood shop. Linda explained that even after her patients left clinic they need to protect their sites "in-between treatments" and "going out and doing outdoors things." She later explained that "they have to protect it, and not let bad germs get at it." Many participants work and have physical hobbies, so they need to have their arm bandaged and enclosed with a garment. The garments should cover the access site to protect it, and the use of smart textiles and antimicrobial fabrics are an option to solve this problem.

*"The Velcro one looked horribly bulky."* The closures of the garments, especially for the openings to the access sites, should not add bulk to the garment, be noticeable, or cause friction on the body. The closures will include the use of invisible zippers, large decorative buttons, flat metal snaps, and magnets. This will allow options for aesthetic preference and for individual closure issues. Sarah had previously seen a patient wearing a self-customized sweatshirt to dialysis with a Velcro access site opening, but she expressed her dislike "I saw a Velcro one and thought it looked horribly bulky." Since Sarah, along with other participants, expressed their distaste for Velcro, no Velcro will be used as a closure option. Velcro can also be irritating to the skin, if it is not placed correctly on the clothing. The chosen closures should be decorative without causing irritation or annoyance with movement of the body.

*"I would love to be able to customize things."* Mass customization is used along side of the user-oriented design process, and both processes begin with the user and their problems to

create solution options. Mass customization will be a vital step in the process of developing apparel for dialysis patients, because they have similar but different needs for their access sites, fit, and finishes. All participants interviewed had a positive response toward the ability to have customized apparel with set options to meet their needs and wants. This process will be used for the development of design ideas and solutions, and for the final design selection, so the garments will have set, standard options for a more inclusive design solution. Even though mass customization options need to be aesthetically pleasing, their function is vital, so they are considered, for this research, as a functional value of design.

Ann explained that for her late husband customizable options "would have cheered hum up to have something that was special for him and he could pick out what he wanted." Jennifer also expressed an interest in the ability to "order anything you need… exactly what you want and exactly what you need." David explained that after receiving a transplant his weight changed often, so having "something customized might be good… I'm more in between sizes now." Andrea expressed frustration with the inability to find properly fit clothing, along with her dialysis clothing issues.

> **Andrea**: "I would love to be able to customize things… my whole life it's been difficult for me to get clothes to fit maybe because things don't tend to look right on me. I mean things are not fashioned for short people they are fashioned for people that are tall and most things are modified for short people."

Allowing the participants to have options to customize to their needs and wants should envoke positivity toward shopping that they previously have not had. Mass customization options will include the ability to choose from specific necklines, arm length, skirt length, skirt style, pants length, access site opening placement, and finishes. There is a standard fit guide for regular, petite, and plus size clothing, but there will also be an option to input custom sizing measurements to ensure a perfect fit.

***Aesthetic values.*** Rosenblad-Wallin (1985) further separated symbolic values into a deeper meaning than aesthetics alone, which includes: self-esteem, fashion, respectability, status, and overall exterior appearance in public. This study, as previously stated, refers to symbolic values as aesthetic values to also include: aesthetics, color, culture influences, and style. This was done, because this study felt that "symbolic values" did not accurately describe what participants need and want related to apparel. The aesthetic value is more than emotions and how the user feels about their exterior appearance related to clothing. The design, style, colors, and mass customization design options are included in this value. For this study, colors, concealment, and overall style were specified as aesthetic values.

*"I would rather have bright colors."* The colors and patterns on garments worn by the participants were found to influence their mood. Colors should be brighter and include fun, stylish patterns. Jennifer expressed her disdain for dark, depressing colors of her dialysis sweatshirts stating "I would rather have bright colors." The garments should not stand out too much, and remain with current stylish color palettes. Trendy colors and brighter, darker color and pattern choices will be used to appeal to a wider consumer base. Due to staining issues, some colors and patterns will have dark options, but these will still be stylish and aesthetically appealing. The objective for colors and patterns is to not have a depressing, melancholy feeling.

*"I was so embarrassed."* The need to fit in with society and be respected is a key priority for the design solutions. The access site openings and any closures added to garments should not make the wearer stand out or look different than others in public. Sarah, and other participants described the disrespectful and depressing emotions that occur when a stranger in public pointed out their access site stating "that's totally embarrassing it happened once and that was enough… I was so embarrassed." The goal is to have garments that meet their needs, but that look as

fashionable as any mass produced, mainstream apparel available. The ability to conceal dialysis patients access site and swelling is a challenge, but can be done with the proper use of fabrics and placement of closures and decorations on garments. The garments will be designed to conceal access site swelling, cover the access site, and conceal the access site openings.

*"It builds your confidence."* The overall style needs to be business casual, but have the ability to be dressed up or down. Business casual was chosen as the overall style, because current clothing worn by dialysis patients was described as "workout" or "gym" clothing. The patients crave more style and a "nicer" daily look for themselves, so business casusal meets this need. Sarah implied several times that being able to wear "nicer" and "dressier" clothing "builds your confidence." Business casual also allows any patients working or going to other daily activities before or after treatment the ability to easily fit in without needing to change. Participants, such as Stacy expressed an interest in stylish clothing because "it would save me from having to carry anything with me." The clothing needs to be loose and flowy, and ensure comfort and concealment. Modesty is a large factor, so the apparel does not need to be revealing and age appropriate to meet a variety of people. Finishes need to be concealed or not obvious they are there. Zippers should either be placed on the garment in a stylish way or hidden under a piece of fabric.

**Develop Ideas and Solutions**

Two inspiration boards were created, one for females and one for males, to capture the overall style aesthetic and color palette goals of potential design solutions. The inspiration for this study was formed from thinking about the opposite of dialysis. Images of light, airy, and soft objects, including birds and feathers, were chosen. The dialysis process was thought to be medical, white, harsh, plastic, rough, and "tethered down" to a chair, so the use of birds and light

images for inspiration was aimed around the opposite of dialysis. Bright, jewel tones and darker color tones were chosen, because they are considered cheerful, fashionable, and can aid with any disguising and staining issues in a more fashionable manner. The inspiration boards can be found in Appendix D and E.

After the inspiration boards and color palette were created, several rough sketches were initially mocked up and rendered. Initial sketches were hand sketched with pencil and black pen, and some later sketches were rendered in color before final design solution choices were made. The sketches depict initial ideas thought of while transcribing interviews and after prioritization of demands into functional and aesthetic values. Figure 7 shows four examples of initial design solution ideas for women's apparel, which included access for the chest, upper and lower arms, and hidden thigh access ideas. Figure 8 shows three examples of early rendered sketches of initial design solutions for women, before a final selection was made. Figure 9 shows examples of initial design solution ideas for men's apparel, which included chest, arm, and leg access. Figure 10 shows examples of initial rendered design solution ideas for men's apparel, that included arm and leg access.

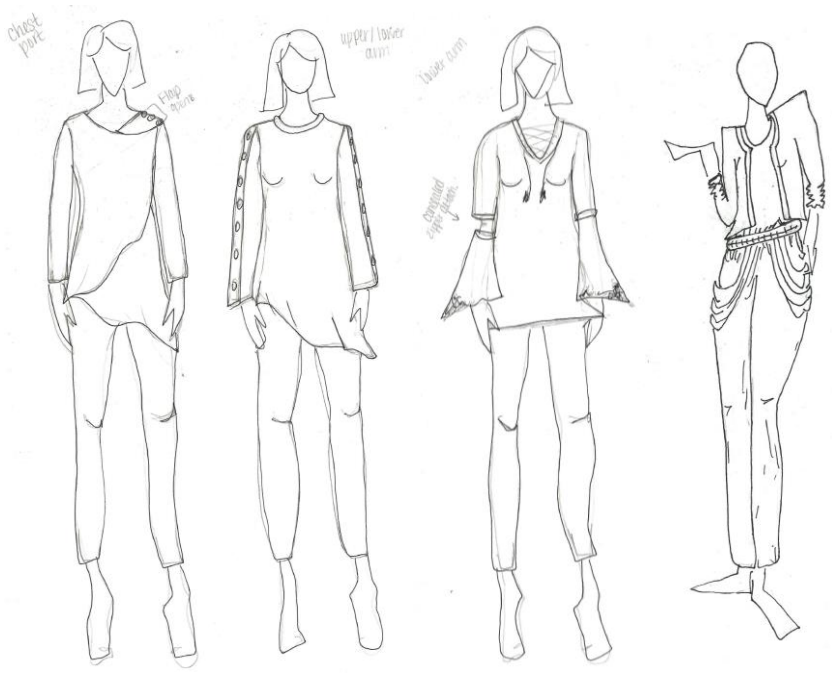


**Figure 7. Examples of Rough Sketches of Women's Apparel Design Solutions**


**Figure 8. Examples of Initial Rendered Sketches of Women's Apparel Design Solutions**

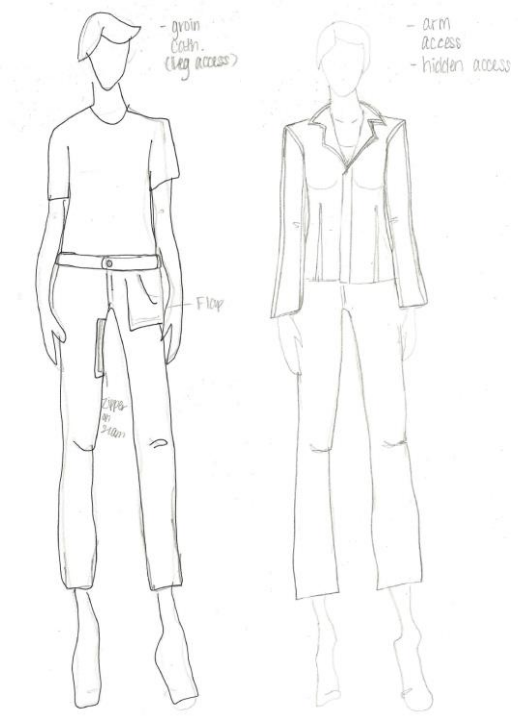


**Figure 9. Examples of Rough Sketches of Men's Apparel Design Solutions**


**Figure 10. Examples of Initial Rendered Sketches of Men's Apparel Design Solutions**

**Evaluation and selection.** After several initial ideas and sketches were formed from the use-situation, demands, and functional and aesthetic values, two sets of designs were selected and rendered as final solution options for men and women. Women's apparel solutions include a shirt with leggings and a dress with leggings, and men's apparel solutions include a casual t-shirt with pants and a dressier button-up shirt with pants. Figure 11 depicts each of these selections for men and women as standard designs with no mass customization options. Designs for both men and women were chosen based off of prioritization of the functional and aesthetic values discovered from the participants. Both men and women wanted soft, comfortable clothing that protected their access sites, worked with the blood pressure cuff, easy access to their vascular sites, and were loose and flowy.

The women's apparel includes a flowy tunic top with a slight elastic cinched waist to accentuate all body types but not restrict bodies with weight fluctuations. The dress is a trapeze style swing dress with a slight empire waist to accentuate all body types. The skirt length can be lengthed or shortened to meet all needs for various heights. This type of dress is stylish, while functional to easily cover any access site, keep patients warm and comfortable with the material and loose, airy fit. Both the top and dress are made out of stretchy knit that moves easily with the body, so it's flowy without being too tight or loose. The leggings can be worn with any style top or dress, and they come in a comfortable, slim fitting style. Color options for the leggings include black and gray. The tops and dresses kept with the style inspiration of dark bold jewel tones and bright prints.

The men's apparel includes a loose but fitted t-shirt option that is available in various colors of prints of darker earthy tones and simple patterns. There is a henley, baseball style, long sleeve t-shirt, and a layered short sleeve over a long sleeve style depicted. The button-up shirt

options include various color and pattern options with rolled and long sleeves. Both shirts are made out of a knit stretch that easily moves with the body that is not restricted like many dress shirts currently available. Many men participants experienced frustration with the inability to have a dress shirt fit around their arms or button them up, so a stretchy knit will solve fit issues related to weight fluctuation and arm swelling. The designs are comfortable, loose but fitted, stretch easily, and accentuate all body types in a flattering manner.

The materials chosen for both men and women's apparel is cotton, modal blends, and cotton, lyocell, spandex blends. These fabrics were chosen based off of the data collected from the participants only. Modal with cotton was chosen because it is a type of rayon, so it stretches well, holds its shape well, it is breathable and can be antibacterial, it washes well, and is wrinkle resistant. Lyocell cotton blends were chosen for similar reasons, but modal may be a better option because Lyocell fabrics can be more expensive and need more delicate washing and care. The materials should be thin enough to work with a blood pressure cuff, stretch easily and maintain shape. Smart textiles and other knit materials are also viable material options that could be implemented into the mass customization apparel design solutions as solutions to keep patients warmer during treatment. The material chosen for the leggings is ponte, which is a knit fabric that stretches with a slimming effect, and they wash-well and are wrinkle resistance. The materials for the men's pants chosen were denim and khaki cotton materials with spandex to stretch easily. Some men's pants have the option to include a spandex stretch top for PD patients and others that need a more comfortable and stretchy fit around their waist and hips.

**Figure 11. Men and Women's Standard Design Solutions Selected**

***Mass customization options.*** Both design solutions, for women and men, includes a set of mass customization options for the sleeves, neckline, closures, and access sites. Women's apparel standard options include the sleeves and neckline. Both designs have standard options of sleeves that include: short sleeve, ¾ sleeve, long sleeve, and bell sleeve options. Both designs also have standard options of neck lines that include v-neck, scoop, square, and round necklines. The dress options may include skirt length, which would be mini, midi, and maxi lengths. Men's apparel standard options include the sleeves and neckline, as well. Both shirt options are available with sleeve options that include: short sleeves, long sleeves, and ¾ sleeves. The t-shirt has neckline options that include: round, v-neck, and henley.

Along with standard options for the apparel designed, access site openings were implemented for the chest, thigh, and lower and upper arm. The options may change based on

the design of the top for both men and women. There are set closure options of buttons, metal snaps, zippers, and magnets. Many of the closures may use faux buttons, added material, or other decorations to conceal the real closures, and some designs leave the access site openings showing in an aesthetically pleasing form. These designs allow for minimum skin exposure, while clearly showing their access site when opened. Chest and thigh catheter access site openings include one option for each design solution, because not as many participants had these site locations. The upper and lower arm locations have at least two options each, because these were the most problematic and common access site locations for men and women. Catheters for peritoneal dialysis are depicted in Figure 18, which shows a unisex design solution with a pouch in a shirt and elastic waist pants with a pocket that the catheter can be stored. Only one solution was mocked up for men and women together, because not as many participants were on PD and the need is for protection and ability to roll up the catheter easily. This solution allows for comfort and protection of the catheter.

Figure 12 shows the women's top option with a knit material flap panel on shiny ponte leggings with a zipper closure to have easy access to a thigh catheter. The tops for Figure 12 and 13 are shown with different color and pattern option styles avilable, as well as, necklines and sleeves. The flap opens to expose the catheter, but looks like an added design with exposed zippers on the lower calf for decoration. Figure 12 also shows a chest catheter option on the top with a flap on the right side that can unbutton and lift open to expose the chest catheter area only. The dress in Figure 12, features buttons on top of the shoulders and arms that can be unbottoned for the chest and lower arm access.


**Figure 12. Women's Thigh and Chest Access Site Top and Dress**

The upper and lower arm access site options on the top design are shown in Figure 13. Any of the designs will work with the lower arm access site, because it's priority is concealment and ease of rolling the sleeve. The first design has cut-out shoulders with buttons that detach the sleeves for upper arm access, but the sleeves may be buttoned back or worn like long gloves unbuttoned during treatment. The second design features cut-outs that slightly exposes that arm with small openings and button closures all the way down the arm. This style allows the wearer to open the sleeve as much or as little as needed for blood pressure and access to their vascular site. The third option features a crocheted bell sleeve that has a concealed zipper under a flap of material. The crocheted part of the sleeve may be removed and worn as a ¾ sleeve, or removed during treatment for a lower arm access site. The fourth option features a side panel on the sleeves going up to the elbow with either an exposed metal zipper or buttons, so the sleeve may be opened and rolled up easily for arm access.

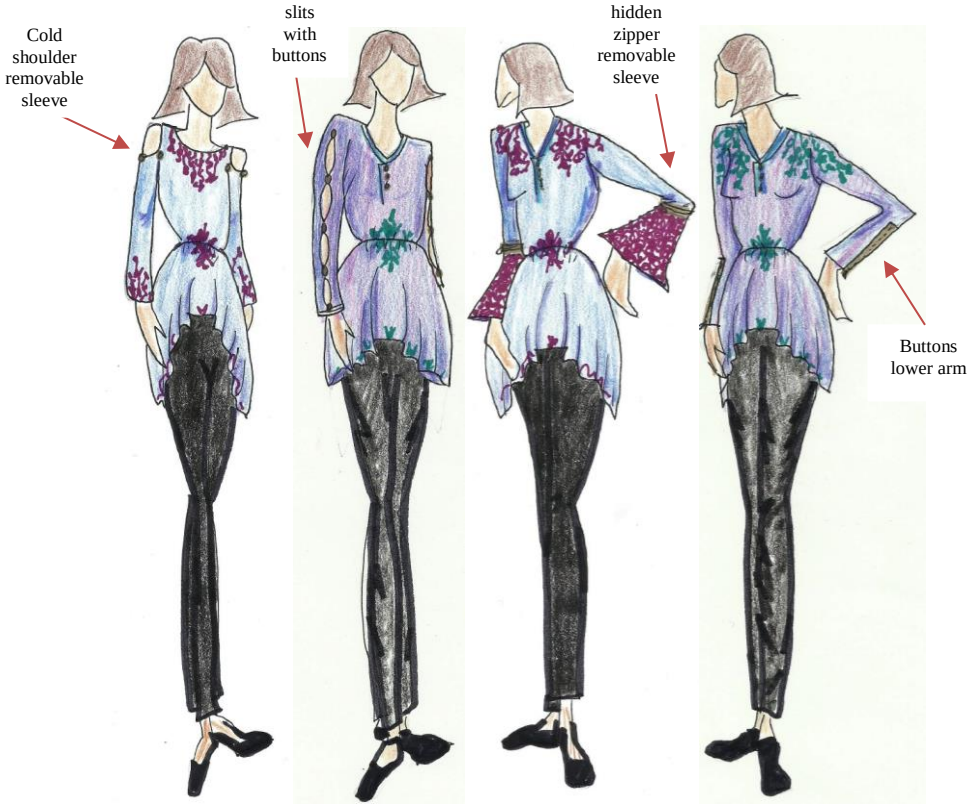


**Figure 13. Women's Upper and Lower Arm Access Site Top Design**

Figure 14 depicts five upper and lower access openings on the dress designs that are similar to the access site options to the women's top. The dresses are also shown with variations of color and pattern options, as well as, necklines and sleeves. The first design option features the same cut-out button closure to access any part of the arm and be able to close it up easily for limited arm exposure. The second design option features a button up decorative panel on the lower sleeve for lower arm access and/or to roll up the sleeve easily. The third design option features the same crocheted removable lower sleeve as the top design. The fourth design option features a hidden, invisible zipper or magnetic closure that is sewn into the seam line, so it is not noticeable to the eye. The sketch has the area highlighted in yellow to see it easier for design purposes. The last design option features the same cut-out shoulder option as the top above.

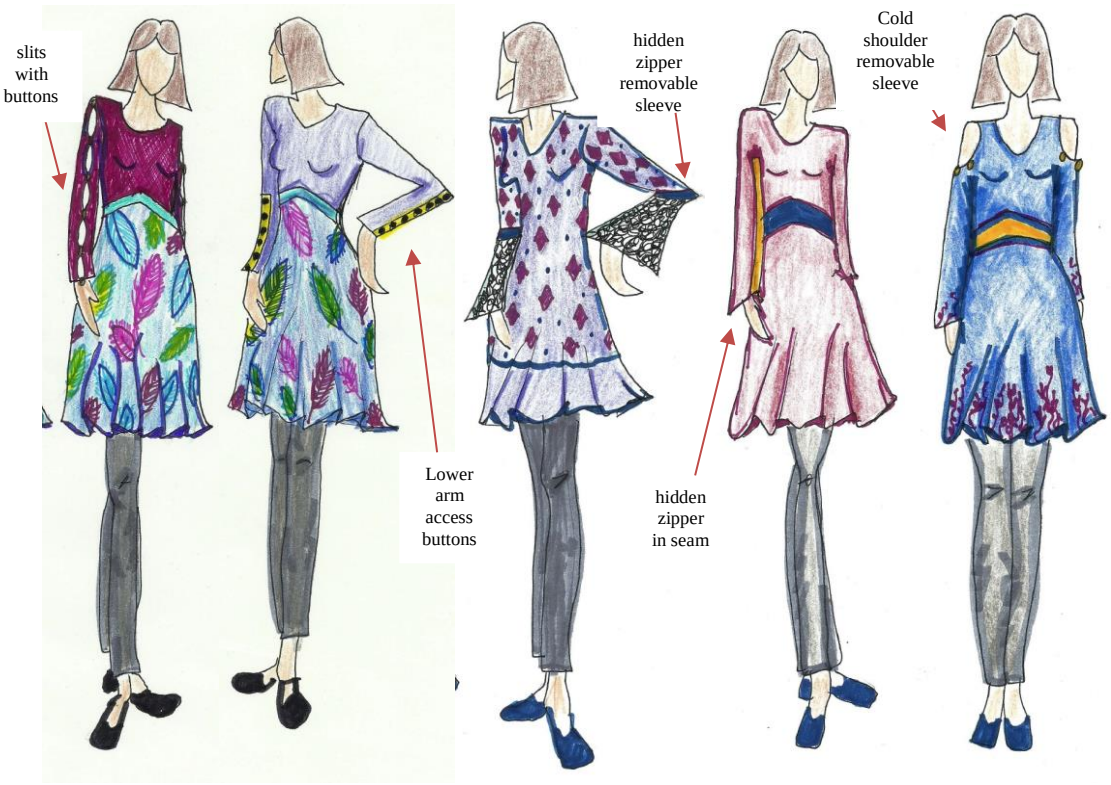


**Figure 14. Women's Upper and Lower Arm Access Site Dress Design**

The men's design solutions include a t-shirt and button-up shirt with pant options. Figure 15 depicts the thigh catheter and chest catheter options for each design solution. The pants on both sketches show a cargo, panel pocket that is actually a flap that can be lifted for easy access. This can include a zipper or magnetic closure option. The chest option for the t-shirt features a henley baseball style t-shirt with a concealed or exposed zipper option at the seam line where the sleeve attaches to the body. The area is depicted in dark green at the chest area. The dress shirt features an upper panel of gray fabric from the shoulder to the upper chest, with button or zipper closure option. This design also has a removable collar and/or panel (colored gray in sketch) with buttons, snaps, or magnets for ease of access to the chest port. All closures would be permanent but hidden under the collar in the collar band panel of the shirt so the neckline would be easier to pull back for chest access.


**Figure 15. Men's Thigh and Chest Design Options for T-shirt and Button-Up**

The men's t-shirt design solutions for the upper and lower arm are shown in Figure 16 with long sleeves in a layered, henley, or plain long sleeve style options. The first two sketches depict the layered short sleeve t-shirt over a long sleeve. The first one includes concealed zippers around the lower blue stripe to remove the long sleeve portion, which can be worn this way or used for access of a dialysis patient site for treatment. The second option includes the ability to remove the entire sleeve and leave a thick tank top style, which has a zipper or decorative button closure around the arm shoulder seam to the arm pit. This is shown with the thick blue lines highlighted around the shoulder seam and arm set-in on the top of the sleeve. The third and fourth sketches depict two style options, henley baseball style and the layered sleeve, both styles include a concealed invisible zipper following the inner arm seam line for easy arm access. This uses a double zipper for limited arm exposure during treatment. The last sketch has a khaki

colored belt, ribbon style piece of fabric that conceals a zipper or magnet closure on the outer arm for easy arm access and limited arm exposure.


**Figure 16. Men's Upper and Lower Arm Design Options for T-shirt**

The last five sketches in Figure 17 represent the button-up shirt options for men's design solutions with mass customization options. The first and second depicts a similar concealed zipper or magnet closure along the inner seam line on the arm. The first sketch shows the sleeve unrolled, and the second is a fixed rolled sleeve style. The third and fourth option have a magnet or button closure removable cuffs. The third shows a rolled faux cuff, so the sleeve can easily be rolled up further and conceal upper access sites and some forearm sites. The fourth option shows a unrolled faux cuff to conceal lower arm access sites and allows for easy rolling up of the sleeves. The last sketch is a light knit sweater with cuffs and a collar, and even though it looks layered the design is only the light sweater. The sleeves can be removed with a concealed zipper

or decorative buttons for easy upper arm access, which is highlighted in blue along with shoulder and arm set-in seam line.


**Figure 17. Men's Upper and Lower Arm Design Options for Dress Button-Up**

Since this research did not have many peritoneal dialysis patient data collected, the needs were limited to weight fluctuation, concealment, and protection of the access site. The other designs aid with the weight fluctation and concealment issues that may arise with peritoneal dialysis, but the catheter may still have issues with protection and keeping the catheter rolled up against the body. The first sketch in Figure 18 is a pair of pants for men or women that feature a soft cotton blend elastic waistband with a pocket to roll the catheter into. This can be used as waistband on any pants style as long as a shirt can cover the band. The second features a rough sketch of a small pocket added to a thicker material shirt, so the catheter does not show, but it will keep the catheter rolled up and protected from the body and the environment. The pouches

are made with similar materials as the other clothing designs that are anti-bacterial and moisture resistant, so the catheters are at a lower risk for infection.


**Figure 18. Unisex Peritoneal Dialysis Shirt and Pant Design Solutions**

Lastly, a jacket for men and women was designed with all access sites options on one jacket. These designs are meant to be a solution for the current dialysis patient clothing currently available with multiple access site locations, but more aesthetically pleasing. This design is both functional and aesthetically pleasing, based on the functional and aesthetic values found from the study. Figure 19 shows the two options designed for men and women. Both jackets have a motorcycle, biker stylish aesthetic. The design solution was to be the opposite of a workout or sweat suit style jacket, and be fashionable enough to wear for treatment and day-to-day activities. The men's jacket includes upper zippers on the chest, flaps and zippers on the upper and lower arms for easy access, and decorative zippers and closures for added style. The women's jacket is a trendy bomber biker style with similar upper and lower arm zipper openings, chest zippers and

added decorative zippers. The patients could wear them during dialysis to aid with keeping warm and continue to wear when they leave. T-shirts or tank tops could be worn underneath these during treatment.

**Figure 19. Men and Women's Dialysis Jacket Design Solution**

**Final Solution.** After all final design ideas were selected with set mass customization options for men and women, one design was chosen for each as a final solution to create a prototype. Typically with the user-oriented design process, the design solutions would be created and given to participants to wear test for feedback before a final solution was created. Since this research is limited on time this was not a possibility, so the final design solutions were chosen based on the best fit of the functional and aesthetic values found to be made into a prototype with each access site opening option. Prototypes were created by the researcher, because of time constraints to be manufactured final fabric garments were not made for this study. The basic top for women with a peplum elastic waist and loose bell sleeves, and the button-up top for men with

removable collar and cuffs was made into a prototype. The prototypes were designed with the standard size of medium for men and women, and made with a dark jersey knit that mimicks the material to be used for the final apparel designs. The men's collar and cuffs were attached with Velcro to show how they could be removed. Photos of the prototypes are in Figures 20, 21, 22, and 23.


**Figure 20. Men and Women's Prototypes- Front**

**Figure 21. Men and Women's Prototypes- Back**


**Figure 22. Women's Prototype Close-Up**

**Figure 23. Men's Prototype Close-Up**

# CHAPTER 5

# CONCLUSION

Chapter 5 contains the following sections (a) summary of findings, (b) implications, (c) contributions, (d) limitations and future research.

## Summary of Findings

The aim of this study was to explore clothing needs and wants of dialysis patients, and apply those needs and wants, using the user-oriented design process for mass-customization, to create suggested clothing products for this target market. First, the study began to identify the problem of dialysis patients use-situation and demands related to mass produced apparel and dialysis and their daily lives, which answered research question 1: To understand how the traditional design process and mass apparel production are failing to meet the clothing needs and wants of PLWD, specifically for people on dialysis. Second, the study discovered dialysis patients functional and symbolic values for clothing, and suggested improvements for current adaptive clothing, which answered research questions 1 and 2: To explore how the current design processes could be adapted to incorporate the user-orientated design process for mass customization of clothing for people on dialysis. Finally, the researcher then prioritized their use-situation, use-demand, functional and symbolic values, and suggestions to create clothing products for this target market, which answered research question 3: To apply the user-oriented design process for mass-customization to the clothing needs and wants of people on dialysis and create suggested clothing products and product distribution channel for this target market.

In defining dialysis patient's use-situation and demands and exploring research question 1, data analysis revealed three theme categories for their situation. The first theme category compared the use-situation of the various dialysis treatment options and locations patients can use for treatment. Three smaller themes emerged from treatment that included: in-clinic hemodialysis, which was revealed to be the most restricting treatment, and at-home hemodialysis and peritoneal dialysis. While most patients felt, it was an "evil path" they were led down, at-home hemodialysis and peritoneal dialysis allowed patients to have more of their "life back," but overall revealed that dialysis was still a "daily monotony."

The second theme category revealed patient's extreme physical feelings during their dialysis treatment, both for in-clinic or at-home. Their similar feelings of "the desire just to rip out the needles and run," resonated with each patient interviewed. The physical feelings further identified use-situation needs dialysis patients had during treatment. Within the physical feelings theme, three smaller themes emerged. First, the extreme temperature sensitivity was felt by all patients, at some point during their treatments, no matter if they were in-clinic or at home. The data reveals that extreme feelings of being cold and "shivering" show that not only is current apparel failing to meet their needs, but that the clinics have disregarded these feelings, as well. Second, patients expressed the feeling of being "trapped in this chair," during their in-clinic and at-home treatments. It was discovered that many patients felt immobilized, because they are not allowed up during treatment and many have limited arm mobility. Lastly, exhaustion appeared as the last major physical symptom patients can have before, during, and after treatment. This was usually worse or better depending on the type of treatment, fluid retention, and other medical issues.

The third theme category appeared with physical feelings, which included "one huge roller coaster ride" of emotions for the patients after beginning dialysis. This theme category fully explored how patients feel, not only during treatment, but also in their day-to-day lives. This theme revealed three smaller themes. There is a "grief process" that patients go through, because they feel they have lost the life they had before starting dialysis treatments. This shows the patients no longer feel or think they look like themselves, which leads to depression, anxiety, and anti-social behaviors. The common theme of "hate" toward dialysis was felt by all patients, even though they knew it was the only way to keep themselves alive. This feeling was described as a "fight" to go to treatment and carry on in their lives as "normal" as possible. The patients all were motivated to stay strong and overcome this period in their lives though, expressing that "you can always find the good with the bad."

In defining use-demand, i.e. functional and symbolic values for dialysis patients, which answered research questions 1 and 2, five theme categories emerged. The first discovered that patients feel there is a functional versus style aspect to their clothing, which was referred to as a "dialysis uniform." The data found that most patients have two separate wardrobes, which includes their dialysis clothing and their day-to-day clothing. Most people have separation in their wardrobe, such as casual clothing, special occasion clothing, and outside clothing, but dialysis patients have an added separation. During the interviews, some patients did not realize they separated their wardrobes, but they did by describing their daily life clothing differently than their dialysis clothing. This theme revealed a need and a want of clothing that could take them from dialysis to their daily activities or vice versus without needing the separation.

The second theme that emerged from use-demand is the patient's access site, which further developed into three smaller theme categories of protection, swelling, and concealment.

The access site was found to be a symbolic and functional need related to clothing. Functionally, the access site needs to stay protected and most patients expressed a need to be "extra, extra careful" with their sites. There is a need to keep access sites clean to keep infection risk low and covered, especially outside, to keep the site from being bumped or hit with any foreign objects that could disrupt it. The access sites can be infected and/or damaged easily by something or someone touching or hitting it, so patients feel the need to special care of the site. Current apparel cannot always meet this need, because it may not cover the site properly, it may not keep the site protected enough during activities, and it may not keep the site clean enough.

The data also showed that many patients have an issue with their access site swelling and changing in size often, which was observed more often for fistula access sites. The swelling in the arm, effects how shirts fit patients, and many felt they could not purchase shirts that did not stretch around their arm easily. The patients expressed a need to not show the difference in their arm size, so they purchased larger clothing instead of clothing that fit them properly overall. Finally, the data revealed that most patients had a vital need to conceal their access site for personal modesty. Most did not want the public to see their sites and ask questions, and/or think they looked different than anyone else. Many patients often revealed they just wanted to feel and look "normal." This reveals a symbolic need to have clothing that is not only modest, but also clothing that gives the patients more self-esteem when in public.

The second theme category in defining use-demand for dialysis patients is the blood pressure cuff and the need "to disrobe to put the cuff on." This theme was not previously known before analyzing the data in this study. The main issue was found to be that patients must always wear a blood pressure cuff during their treatment, and that it limits arm mobility and restricts their clothing choices. The issue with clothing was found to be that thicker, long sleeves cannot

be worn on the blood pressure cuff arm, because it will not take an accurate reading. The patients wished there was a way to stay warm without needing to have both arms exposed during their treatment.

The third theme category for use-demand was revealed to be an issue with staining from cleaning solutions and/or blood during dialysis patient's treatment. The data showed that most patients either wore old, stained clothing and changed, or they wore mostly dark colors that would not show staining easily. Patients did not indicate they would wear "nice" clothing during treatment, out of fear of the clothing being "ruined" from staining. Staining was found to be an issue for many patients, and resulted in a need and want from most for a stain resistant fabric.

The fourth theme category for use-demand was found to be weight fluctuation from fluid retention, medications, and stomach swelling from peritoneal dialysis. This resulted in clothing issues, because many of their current clothing no longer fit and they did not want to purchase various sizes of clothing to meet their weight needs now. Most patients revealed that they purchased oversized clothing and continued to wear it no matter their weight fluctuation, so they always had clothing to wear. There appeared to be a fear of not having clothing that fit and being uncomfortable, especially during their treatment. Many expressed that they would rather have clothing that was too large than to be uncomfortable in tight clothing.

The last theme category for use-demand was current design solutions, which included current adaptive dialysis clothing and any patient self-customization of clothing. While many patients had seen or at least heard of the current adaptive dialysis specific clothing available, most had not purchased any of the items. The data affirmed that the current available clothing is expensive, "not attractive," and that the designs made the wearer's stand out in public. While many agreed that the zippers on each arm were a benefit for the access site and blood pressure,

there is a need to conceal or place the access site closures in a fashionable manner. Along with hemodialysis clothing, peritoneal dialysis belts were also discovered after data analysis. While the belts were an initially good idea, most patients revealed it was hard to keep them clean, they are expensive, uncomfortable, and that they are bulky and show under clothing.

Self-customized solutions were found to be something that many patients had tried or had seen others try to do for treatment use only. Most patients that had gone to a professional to have clothing made for their needs confessed that it was too costly to make. Other participants did not want to "ruin" their current clothing, even if it was only used for dialysis. Some patients had seen others with outfits made specifically for dialysis, which included: slits in arms, jumpsuits, and sewn in zippers at their access sites. Patients that had customized something stated that many attempts failed, because the garment did not work with their blood pressure cuff or their design idea did not execute correctly.

Prioritizing use-situation and use-demand for dialysis patients, shed light on what the patients wanted their "ideal" dialysis and day-to-day apparel to be including: fit, fabrication, colors, and overall style, satisfying research question 3. The first theme category was called fit for dialysis patient's clothing. Everyone is "built differently, but some clothing makers don't think about that," was affirmed from data analysis. The want and need to have clothing that not only fits properly, but clothing that is loose, flowy, and is comfortable is priority. Participants informed that they did not want tight, clingy clothing because it would either bring attention to their weight fluctuation and/or their access sites. Looser fit around the abdomen and arms were important for patients.

The second theme category was fabrication that included soft, stretchy fabrics that are wrinkle-resistant, warming, and long-lasting. Most patients expressed a want of cotton-like

materials that stretch and are soft to the touch. They did not want anything else irritating on their body, because they already have access sites and other issues. The ability to stay warm during treatment is a priority for patients, so having a fabric that can insulate to keep them warmer than their current options is essential. The want of wrinkle-resistant clothing came from the long periods of sitting during treatment, so they did not want to have clothes that were extremely wrinkled after sitting. Finally, the ability to have clothing that washes easily, does not stain, and is long-lasting was a want of most patients.

The third category focused on colors and patterns of clothing. Most patients revealed they wore darker colors to help with staining issues, but most wanted to be able to wear brighter, cheerful colors, rather than depressing dark colors. The clinics were found to be a medical, melancholy evoking environment, so patients felt that if they could wear pastels or brighter colors it would improve their mood and the mood of others around them. Most patients did not express a want of bold, gaudy patterns, but fashionable, modest colors and prints appealed to their style wants.

Finally, style was discovered as the last theme category. This category communicated the wants and needs participants related to their "ideal" dialysis clothing that would be able to carry them over into their day-to-day lives. Most patients revealed that they "have to really hunt" when shopping for apparel to meet their dialysis and day-to-day life clothing needs. Since most patients shopped for function over style, the shopping experience was no longer enjoyable to them, so it became a chore and a hassle. The overall want was to have clothing that worked for dialysis and their day-to-day life without needing to change. Even patients that had their dialysis treatment at-home stated that it was a hassle to have to change after treatment, and wished they could "run out the door" after their treatment. The overall styles that were found to be the most

important include: ease of access of both arms, aesthetically pleasing, fashionable, look the same as mainstream apparel, concealment and modesty, and be comfortable but stylish. A business casual aesthetic was found to be the best overall description for the styles that would best meet patients' needs at treatment and in their day-to-day activities.

Design solutions were created with the application of mass customization, user-oriented design, and the analysis of patient's wants and needs and the researcher's design journal, which satisfied research question 3. This section dwelled further into the design of clothing to create the functional and symbolic values for dialysis patient's clothing demands, and explained how this study applied the user-oriented design process. The first three steps of the steps of the user-oriented design process deal with the purpose of the study, literature review, methods, and research questions sections of this study. The fourth step, refers to data analysis of collected interviews and observations. This step discovers and prioritizes the use-situation and demands of the participants, which, for this study, are fully described in the design of clothing section.

The fifth step in the process, formulation of functional and symbolic values, is where the design solution section come in to play. The demands were specified into each value, so that proper ideas and potential solutions could be developed. The functional value focused on protection and comfort, which, for this study, included: fit, fabric, protection, and finishes. The symbolic value included aesthetics, self-esteem, and public appearance, which for this study, included: colors, concealment, and overall style. The clothing designed was business casual to allow a dialysis patient the ability to go to treatment and then straight into their day-to-day activities without needing to change. Business casual was chosen because it fits most participants needs and wants, it could be dressed up or down, and is socially acceptable in most situations.

Mass customization was also used with set options that include: neckline, sleeve length, skirt length, access site opening placement for the thigh, and finishes. Necklines for women included: V-neck, scoop, square, and round necklines. The sleeve lengths for women included: short sleeve, ¾ sleeve, long sleeve, and bell sleeve options. The dress options may include skirt length, which would be mini, midi, and maxi lengths. Men's sleeve options included: short sleeves, long sleeves, and ¾ sleeves. The t-shirt has the neckline options: round, V-neck, and Henley. Access site options for both men and women were: chest, thigh, upper and lower arm access, and peritoneal dialysis catheter options. A size guide was also used to include regular, plus, and petite sizes, with the ability to input custom measurements to ensure a perfect fit.

After the values were specified a series of rough sketches and inspiration boards, i.e. ideas and potential solutions, were created to find the best solution for this study. From these sketches, final ones were selected as final design solutions. A flowy top and dress with leggings were designed for women using the color and pattern inspirations, and a long sleeve t-shirt and button-up shirt with pants were created for men using the color and pattern inspirations. One chest and thigh design option was created for men and women, and two upper and lower arm access options were created for men and women. The peritoneal dialysis catheter was designed with a unisex pouch and pocket to go into clothing for protection and concealment needs. One final physical prototype was designed for both men and women, to show that user-oriented design and mass customization are viable options for designing apparel for all.

## Implications

This study has implications for society, other disabilities, the fashion industry, and academia. First, this research allowed participants in this study to be open about how they feel overlooked as a dialysis patient and member of society, as well as, in the fashion industry.

Throughout the interviews several participants expressed that they did not think they purchased and separated their wardrobe into dialysis clothing and day-to-day clothing, only to realize after the interview that they did. This study's findings show that dialysis patients have, not only a want, but a need for "nice" clothing to wear to treatment, without having to change before or after dialysis. This study also allowed participants to explore and discover why they dressed modestly, and felt the need to conceal their access sites. Most participants expressed a need to fit in and not have a stranger in public stare or say anything about their access site. There is a strong sense to belong and feel "normal" in society, and the participants could discover how clothing can aid with this feeling.

Second, the apparel industry can benefit from this study's findings, and may find it valuable to begin to consider and include PLWD in the design process of traditional clothing. There were 56.7 (18.7%) million people in the United States diagnosed with some type of disability in 2010 (Brault & Census, 2012). Out of that percentage, this study focused on the disability and illness of American dialysis patients, which according to the National Kidney Foundation (2016), 57.3% of patients were male and 42.7% were women in 2013, and in 2016 more than 661,000 Americans had kidney failure with 468,000 on dialysis. This number is expected to grow, and everyone will eventually age and possibly have a disability in the future. This is a large group of underrepresented people in the apparel industry, and this research further shows that they should not continue to overlook them. Current apparel is being manufactured for mainstream markets, and this research shows that these underrepresented groups feel they are limited to only functional clothing. Dialysis clothing is not appealing to them for various reasons, and they want to wear mainstream apparel daily. Unfortunately, they feel limited with their

apparel choices, even though they have the want and the fiscal ability to spend on stylish clothing.

Third, several participants expressed feelings of being overlooked in society as a dialysis patient and/or being clustered together with other disabilities and illnesses, such as chemotherapy patients. While the dialysis patients had a strong urge to not be clustered together with other disabilities, this study found that the functional and symbolic values for their clothing demands can be used for other disabilities to meet a wide range of needs. The point of mass customization and the user-oriented design process is to create products with the user in mind, but also to have inclusion.

Finally, this study's findings contribute to academia research and academic departments in textiles and apparel design. This research can inform future designers that there are people outside of main stream target markets that have apparel needs and wants. This applies to more than PLWD and dialysis, such as plus size, petite, and other disabilities and illnesses. There is a functional need for clothing that everyone must be dressed acceptably in public, but there is also a symbolic need to have fashionable and confidence boosting clothing. It should not be limited to only main stream target markets.

## Contributions

This study has several contributions to the literature. First, the study's findings add to the body of knowledge for PLWD and apparel needs and wants. Dialysis patients and clothing needs have not been researched, and PLWD clothing needs and wants related to the user-oriented design process and mass customization has not previously been explored. Much of the past research conducted in these areas, tried to improve the current disability clothing design processes but lacked introducing or creating new suggestions to successfully implement the

processes into the apparel industry. This research shows that mass customization may be a valid design source to implement into the fashion industry.

Second, this study supported and expanded on Rosenblad-Wallin's (1985) user-oriented design process. Rosenblad-Wallin's (1985) process focused on functional clothing design, with little emphasis on the aesthetic value of clothing, so this research expanded on the process to include not only emotional (symbolic) values but also the aesthetics of a garment. This is not how the user is viewed in society now, but to themselves and in all aspects of their lives. This research also combined the use of the user-oriented design process to include mass customization options. While mass customization places the user at the beginning of the design process, the same as user-oriented design, they have not been combined. This study placed mass customization options into the six steps of the researcher's user-oriented design process. Both processes have been successfully implemented into other areas, such as the automotive industry and the technology industry, but they have not been implemented as much into the fashion industry, even though there is a possibility to do so successfully.

Finally, this study had an aim to adapt the current disability design processes, adaptive and universal design, with the user-oriented design process and mass customization. Both design processes were found to be viable ways to create apparel for PLWD, but both had failed to successfully implement into the mainstream apparel industry market. This study found that by using the user-oriented design process apparel can use adaptive design options to meet the functional value from user-demands, and that the inclusive idea from universal design can be used to meet the aesthetic value of clothing for user-demands, when mass customization is implemented. Mass customization, from the study's findings, is vital for both adaptive and universal design to co-exist in the apparel industry. This is because adaptive design is created

with the function of a garment in mind, whereas universal is created as an inclusive design for everyone to use without looking different, so it is focused on the aesthetic more than function alone. This study found that apparel needs to be both functional and aesthetically satisfying to be properly implemented in the market and purchased. Mass customization gives any user, not only PLWD, the ability to purchase apparel that meets their exact needs and wants. Mass customization allows the user to have the adaptive (functional) apparel they "need," and the inclusive (aesthetic) apparel they "want".

## Limitations and Future Research

As in other research, this study had certain limitations and, therefore, future research opportunities. First, this study highlighted dialysis patients living across the United States. Since the sample size focused on one geographic area, future research could focus on specific cultures and how the cultural aspects of dress influence their needs and wants related to apparel. This could influence the overall style, colors, patterns, modesty, and concealment related to dress. Focusing on a specific culture could also change the needs and wants of apparel, since a different type of user and use-situation would be the focus.

Since this study did not specify gender, age (other than 18 and up for IRB purposes), or ethnicity, future research could also look at more specific demographics of dialysis patients. This could influence the style of clothing designed, the closures needed, access site locations, and donning and doffing the garments. Millennial participants might want more youthful and trendy styles, whereas Generation X participants might want more basic and modest styles. Different genders have different needs and wants related to apparel, as shown in this research. Focusing on only women or men would allow for more insights on their use-demands and situations.

This study only focused on dialysis patients, which is a small percentage of PLWD. Future studies could focus on other smaller and/or overlooked disabilities and illnesses in research to find their apparel needs and wants using the user-oriented design process. Future research could also apply the user-oriented design process and mass customization to disabilities that are vastly different from dialysis patients to see if similar positive results are discovered using the processes.

This study was limited on time and ability to produce final garments to gain feedback from participants, which is an important step in the user-oriented design process. Future research could take this research a step further and create final garments to get feedback from participants and select a final design solution. Since the final garment solutions could not be produced, the proposed designs could have unforeseen spacial issues related to closet space, weight on the body, and space while sitting at dialysis. Future research could produce the garments, and perform a wear test to observe any spacial issues related to storage, cleaning, and standing and sitting in public with the garment on.

Final materials for the garments designed were not a large focus for this study, since the focus was more on the design processes suggested. The material options were not wear tested and information for fabrics were based on participant suggestions there is limited ability to know if they would work or not for the participants functional and aesthetic values. Other fabrics may be more sustainable and meet the needs of the participants more efficiently. Future research could be conducted to focus on materials to better meet participants functional and aesthetic needs using smart textiles, and/or a study based on textiles to meet the needs for dialysis and even chemotherapy patients. Final garments could be created and brought back to participants for feedback to see if they worked during dialysis treatments and day-to-day activities.

Since only two in-person were conducted for this study and the rest were conducted over the phone, participatory observations were limited. Due to HIPPA and IRB, field observations came from afterhours tours of clinics and observations during operating hours only in waiting areas of clinics. Future research could perform more in-person interviews and/or receive permission during operating hours to observe patients receiving dialysis treatments to get a better understanding of apparel issues during dialysis and patient needs and wants of apparel. Since the observations and interviews discovered that participants felt depressed and cold at the clinics, future research could also be conducted on suggestions for remodeling various clinic spaces to improve their feelings. Future research could also look at how the use of color, art, and size of spaces psychologically effects the patients and staff.

Lastly, mass customization is suggested to be used online for apparel design, while participants were asked their preference for shopping online or in-store this topic was not further explored. Many participants, in the study, did prefer or at least enjoyed online shopping, so it was determined to be a viable option. No participants had previously seen a mass customization website and it was not shown to them in this study, but the idea was described to them verbally and received positive feedback. Future research could create a study related to mass customization of apparel for PLWD to find out their opinions on this type of website. A mock-up website could be created with the user-oriented design process to see if it is a viable solution for this study.

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## APPENDIX A:

## INITIAL IN-DEPTH INTERVIEW PROTOCOL

**Part 1: Interview Instrument**

### Demographic/ General Information

1. What name would you prefer to be called for the purposes of the research study?
2. Age and gender
3. How long have you been on dialysis?
4. Other disabilities or limitations- Do you have any other disabilities or limitations other than dialysis? If so, what are they?
5. Where is your vascular access site or port located?
6. Do you work? If so, can you explain what you do?
7. Are you married and/or have a family?
8. Are you involved in any social activities? If so, what do they include?

### Identification of Problem- Use situation/ demand

9. How do you feel about where your access site is located?
10. Tell me about your experience since beginning dialysis treatments.
11. Tell me about what you experience while having a dialysis treatment, i.e. emotional and physical
12. What do you typically wear when you receive dialysis treatments?
13. Tell me a story about a time apparel did not work with your treatment.
14. Tell me about your daily activities and life outside of dialysis treatments
15. Typically, where do you go before and after your treatments?
16. How do you feel when you wear the same clothing for treatment and in your daily activities before/after treatment?
17. What issues do you have with current apparel you wear to dialysis and in daily activities?
18. Tell me about what you look for in apparel when shopping.
19. Tell me about how your access site influences your clothing purchases.
20. Describe a clothing item you have purchased and did not like. Why?
21. Describe a clothing item you have purchased and did like. Why?

### Formulation of Objective- functional and symbolic value

22. Tell me about an issue you face related to dialysis and apparel.
23. What are the important physical properties of a garment for you?
24. Tell me about what you typically look for in apparel based on aesthetics and visual alone.

25. Does your culture influence your apparel purchase decisions, i.e. modesty, colors, etc.? If so, what does that include.
26. Do you feel you dress more related to function or style? How so?
27. What brands do you look at?
28. Do you look at clothing online, i.e. Pinterest, Instagram, blogs?
29. What kind of clothing or style do you idealize?
30. Do you have a celebrity style you model after?
31. How fashion involved do you think you are?

**Application of Mass Customization and User-oriented design- user-needs/situation**

32. Describe your ideal outfit for dialysis treatments.
33. Describe your ideal outfit for day-to-day activities and/or your occupation.
34. Tell me where you typically purchase your apparel, i.e. in-store, online, catalogs?
35. Have you customized or adapted any apparel to better meet your needs?
36. Have you had any apparel items tailored to meet your needs since starting dialysis? If so, what are they?
37. What are your feelings about having the ability to customize your apparel to meet your current needs?
38. Have you customized any of your clothing through online retailers? If so, describe the process you went through.
39. Are you aware there are online retailers that sell apparel for people that vascular access sites? If so, which companies?
40. Do you currently or in the past have owned any of this apparel? If so, what did you order?
41. Would you customize your clothing online if you had that option? Tell me how you would like that to work.

***Participants can ask questions throughout interview**

## APPENDIX B:

## STUDY CONSENT FORM

## UNIVERSITY OF GEORGIA
## CONSENT FORM

CLOTHING FOR EVERY ABILITY AND EVERY BODY:

DESIGNING CLOTHING FOR DIALYSIS PATIENTS USING THE USER-ORIENTED

DESIGN PROCESS AND MASS CUSTOMIZATION

### Researcher's Statement

We are asking you to take part in a research study. Before you decide to participate in this study, it is important that you understand why the research is being done and what it will involve. This form is designed to give you the information about the study so you can decide whether to be in the study or not. Please take the time to read the following information carefully. Please ask the researcher if there is anything that is not clear or if you need more information. When all your questions have been answered, you can decide if you want to be in the study or not. This process is called "informed consent." A copy of this form will be given to you.

**Principal Investigator:** Laura McAndrews

Textiles, Merchandising, and Interiors

lauraemc@uga.edu

706.542.6771

### Purpose of the Study

The purpose of this study is to understand apparel needs and wants for underrepresented groups of people, specifically dialysis patients. This study also aims to then apply the needs and wants found to design and develop clothing that can be mass-customized. You are being asked to participate in this study, because as a dialysis patient and may have specific clothing needs that most apparel retailers overlook. Your participation in this research study will aid in the understanding of developing mainstream apparel to better meet every consumer's needs, and to enrich research for underrepresented groups of consumers that currently ignored in the apparel industry.

**Study Procedures**

If you agree to participate, you will be asked to take part in an interview, in which you will answer a series of questions about your feelings about your dialysis experience and daily activities, your occupation and social activities, clothing needs or wants you have, and your personal clothing style. Along with the interview, you will also be asked to give your opinions on some current available apparel for dialysis patients websites, mainstream apparel retailer websites, and then a mass customization apparel website. Your feedback and opinions about purchase intention and design will be inquired. The interviews will last for 1 hour. The entirety of the interview and interactive component will be audio recording with your permission. After the interview, you may be contacted again to give feedback and opinions on the prototypes of clothing designed by the researcher. This feedback may take up to 1 hour of your time, but more than likely less than 30 minutes. Your participation will be voluntary, and if you agree to participate in the study, you will only be asked to take part in the interview. The location will be agreed upon by you and the researcher, and your convenience and comfort will determine location. The interview will be audio recorded, but only with consent of the participant. Your name will not be linked to the data collected to ensure protection and privacy.

**Risks and discomforts**

We do not anticipate any risk from participating in this research study. If for any reason you become uncomfortable or no longer want to participate in the study, you have the ability to stop the interview at any moment.

**Benefits**

As a participant in this study, you may benefit by realizing apparel needs that are not currently met for you, why having clothing made for underrepresented markets is important, realizing the little customizable options that are currently in the market, and how most mainstream apparel companies are failing to meet the needs for everyone. The researcher hopes that this study will positively benefit society through gaining more understanding about the apparel needs, aesthetic and functional, that are currently not met in the marketplace. Through this research, it is hoped that mass customization is a viable option to shop and use for everyone, regardless of the need. This research has the potential to affect how and where we purchase apparel to better meet our needs and fit without the need to tailor or alter.

**Incentives for participation**

Incentives for participation will be given for this study.

**Audio Recording**

An audio recording device will be used in this study. These recordings are needed so the researcher does not have the potential to misquote or misinterpret what you said during the

interview. Audio recordings guarantee that whatever you say is represented and documented exactly the way you stated it. The recordings will be kept for six months after transcriptions are completed and then destroyed.

Please provide initials below if you agree to have this interview audio recorded or not. You may still participate in this study even if you are not willing to have the interview recorded.

_____I do not want to have this interview recorded.

_____I am willing to have this interview recorded.

**Privacy/Confidentiality**

The data collected from you in this study will identify you indirectly with the use of codes when analyzing data. A pseudonym of your choosing will used in the research and only the state you reside in will be used in the study. Your real name will not be mentioned or recorded at in any point in the research. All audio recording will be stored on the researcher's personal computer.

**Taking part is voluntary**

Your involvement in the study is voluntary, and you may choose not to participate or to stop at any time without penalty or loss of benefits to which you are otherwise entitled.

**If you have questions**

The main researcher conducting this study is Elise Brooks, a graduate student at the University of Georgia. Please ask any questions you have now. If you have questions later, you may contact Elise Brooks at evb14109@uga.edu or at 404-944-4221. If you have any questions or concerns regarding your rights as a research participant in this study, you may contact the Institutional Review Board (IRB) Chairperson at 706.542.3199 or irb@uga.edu.

**Research Subject's Consent to Participate in Research:**

To voluntarily agree to take part in this study, you must sign on the line below. Your signature below indicates that you have read or had read to you this entire consent form, and have had all of your questions answered.

| | | |
|---|---|---|
| _____ | _____ | _____ |
| Name of Researcher | Signature | Date |
| _____ | _____ | _____ |
| Name of Participant | Signature | Date |

Please sign both copies, keep one and return one to the researcher.

## APPENDIX C

## RECRUITING MATERIAL- EMAIL

Hello,

My name is Elise Brooks, and I am a graduate student at the University of Georgia in the Textiles, Merchandising, and Interiors Department. I am contacting you today to invite you to participate in a research study related to dialysis patients and clothing needs. Because you are a doctor/nurse in this field and work with these patients daily, I feel you may have a unique view for this research. There are no requirements to participate in this study, other than being a healthcare provider for people on dialysis.

Your participation will involve a one-on-one interview and observation, if possible. This should take about an hour total, but could go up to two hours. The interviews will be audio recorded and handwritten notes will be taken during the observation process. The location of the interview will be left up to your discretion (i.e. your office or public location). The benefit for the study will be to inform myself about this unrepresented group, aid in the research of creating clothing for this group, and realizing information and problems area you were not aware of before the study.

If you agree to participate in this study, a $10 gift card will be given to you as an incentive. You also have the ability to stop the interview process, if you become uncomfortable for any reason but the risk of participation is minimal.

If you would like additional information about this study, please feel free to call me at (404) 944-4221 or email me at evb14109@uga.edu

Thank you for your consideration!

Sincerely,

Elise V. Brooks

## APPENDIX D

## RECRUITING MATERIAL- POSTER

# Research Participants Needed!

- Must be 18 years or older
- Male or female
- Must be on hemodialysis or peritoneal dialysis
- This study aims to explore clothing barriers you experience during treatment and in daily activities related to dialysis. With your help and feedback, a prototypes of apparel will be designed.
- Participation in this research will be one-on-one hour interviews and follow-up email to gain feedback for prototype apparel designs that will be created.
- Potential benefits of research: discover issues currently ignored in the apparel industry, and aid in the research of developing better clothing solutions for you!
- You will be compensated for your time and help.

University of Georgia
Textiles, Merchandising, and Interiors
Dawson Hall
305 Sanford Dr.
Athens, GA 30602

Athens, GA 30602

The University of Georgia

Contact:
Elise Brooks
404--944--4221
evb14109@uga.edu

Dr. Laura McAndrews
lauraemc@uga.edu
706.542.6771

Elise Brooks Phone: 404-944-4221 Elise Brooks Phone: 404-944-4221 Elise Brooks Phone: 404-944-4221 Elise Brooks Phone: 404-944-4221 Elise Brooks Phone: 404-944-4221 Elise Brooks Phone: 404-944-4221 Elise Brooks Phone: 404-944-4221 Elise Brooks Phone: 404-944-4221 Elise Brooks Phone: 404-944-4221

## APPENDIX E

## WOMEN'S INSPIRATION BOARD

## APPENDIX F

## MEN'S INSPIRATION BOARD