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RESEARCH PAPER



# One size does not fit all: a qualitative study exploring the apparel wants and needs of people on dialysis

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## ABSTRACT

**Purpose:** This study explored the apparel wants and needs of people on dialysis using the user-centered design process. The study's aim was to understand the experiences and feeling of people on dialysis and their clothing barriers, along with exploring their functional needs and aesthetic wants in apparel items.

**Methods:** To achieve the study's aim, 15 semi-structured qualitative interviews with people undergoing dialysis or caregivers were conducted in March 2017. In addition, researchers observed two dialysis clinics after hours for additional context.

**Results:** Three theme categories emerged, which included (a) dialysis treatment, (b) challenges of dialysis, (c) dialysis clothing barriers. Within the framework of the user-centered design process, a deeper understanding of both the physical and emotional challenges of dialysis helped in finding barriers and giving design considerations for researchers, industry professionals, and educators.

**Significance:** The findings help to give voice to a target market who desires to participate in consuming both fashionable and functional clothing. Current apparel for PLWD focus on the physical ailment and not the psychological well-being. The study's findings help to give recommendations to researchers, industry professionals, and educators when designing and developing apparel, products, and other environments for people on dialysis.

## ARTICLE HISTORY

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## KEYWORDS

Apparel; dialysis; user-centered design process; PLWD

## ► IMPLICATIONS FOR REHABILITATION

- People undergoing dialysis treatment are an under-served population in terms of clothing needs and wants, which results in both physical and emotional challenges.
- This study recommends researchers and industry professional to apply the user-centered design process when designing and developing apparel for people on dialysis.
- People on dialysis have a similar unappealing “uniform” that is worn during treatment that gives access to their site and blood pressure cuff, hides blood staining and allows for weight fluctuations.
- Apparel considerations for designing should consider to break down clothing barriers and improve mental health of people on dialysis.

## Introduction

Dialysis treatment affects a person both physically and psychologically [1]. Previous studies have found drastic changes to a person's quality of life including psycho-social, emotional and routine everyday aspects of life [2–4]. When a person first goes on dialysis, there is a renegotiation of one's self [5], as well as, a transformation in the perception of one's body and body integrity [6]. Further, a person on dialysis has a loss of freedom, dependency on machines, and a reliance on caregivers [7]. Previous clothing and textiles research has shown that apparel can increase confidence, social skills, and overall life skills, especially for people living with disabilities (PLWD) [8]. At its most basic level, clothing is used for comfort and protection, as well as, boosting self-esteem. For PLWD, clothing can also act as a way to conceal imperfections and shift attention to other areas of the body [9].

Dialysis is a mechanical, medical process used for people who have lost more than 85% of their kidney function and used to remove waste, fluid, and build-up of potassium and bicarbonate in the body [10]. Rushing [11] found that about 550 000

individuals had kidney disease with renal failure in 2010, which is approximately 10% of the U.S. population. Two types of dialysis currently exist: hemodialysis, typically done in a clinic or hospital and uses a vascular access site, and peritoneal dialysis, which can be performed in-home and uses a catheter placed in the abdomen [10]. For the purpose of this research the term “people living with disabilities” (PLWD) will be used as the participant group of people on hemodialysis and peritoneal dialysis.

Traditionally, the apparel industry has designed clothing for mainstream consumers and have continued to overlook the functional and aesthetic needs for underrepresented consumer groups, such as people living with both mental and physical disabilities [12]. Though, the Americans with Disabilities Act (ADA) in 1990 implemented policies for the improvements and modification of public spaces to accommodate PLWD, there are still apparel barriers [13]. Currently most apparel brands design and product develop clothing using the traditional design process, which does not have a mechanism to input consumer needs and wants. This is especially true for those not in the mainstream, like PLWD.

The user-centered design process focuses on the human factor based on the needs and interests of the user and emphasizes products that are usable and understandable. Though the user-centered design process has been applied for the development of other consumer products, this process has been under-utilized in designing apparel for PLWD. Like many design processes, the user-centered framework starts with the identification of a design problem, but at various points of the design process, user feedback is gathered and analysed to find a design solution [12].

Therefore, the purpose of this study was to apply the user-centered design process in identifying clothing needs and wants of people on dialysis. Specifically, the objectives were (a) to explore the users' (people undergoing dialysis) dialysis experience through the lens of apparel and (b) to understand the users' apparel needs and wants including apparel interests, use-situations, and other general demands,

## Literature review

### *Traditional design process*

The traditional design process for the apparel industry is a part of the basic product development process used in business and engineering [12]. Companies utilize the product development process to generate potential products and designs and promotes products with a focus on responding to consumer needs [12,14]. This traditional design process creates apparel products that are mass-produced for mainstream consumers [15]. This design process moves through a linear and sequential process; (a) generate ideas, (b) design; (c) prototype; (d) evaluate and refine; and (e) production plans [16–18]. Apparel that is created through the traditional design process has a focus on profit and a lack of focus on apparel issues and consumer needs of those outside the mainstream [19]. Therefore, with apparel being a necessity and a social standard [20], this creates challenges for PLWD to participate fully in their society.

### *Current design solution for PLWD*

Currently there are two design solutions to aid in the creation of apparel for PLWD; (a) adaptive design and (b) universal design. Both design processes have been popular areas of research and many attempts have been made to cross over to industry [8,17,21], however these processes have continued to unsuccessfully fulfil the apparel needs of PLWD [19].

### *Adaptive design process*

For PLWD, the adaptive design process has been a common solution for apparel products. Adaptive design is the ability to adapt a specific element of a product when circumstances require, while maintaining the general product use and design. Many times, the product adaption comes in the form of add-on accessories or attachments [22].

Adaptive design was developed to improve technology, computer systems, engineering systems, architecture, automobiles and other transportation [22]. Then in the 1950s, adaptive design shifted to the apparel industry with a functional aspect for dress that provided protection and comfort such as raincoats, boots and ponchos [23,24]. Some common examples of adaptive design products for PLWD include magnet closures, hook and loop closures, easy pull-tab zippers and garments with other openings to ease with donning and doffing of clothing. However, while these are functionally beneficial for apparel, these features are not always the most fashionable and aesthetically pleasing [23].

Overall, adaptive design has remained a dominate design solution for PLWD and/or unique dressing needs. Past research utilizing adaptive design has been for the medical and disabled communities like Sau-Fun, Chi-Leung, and Lai-Fan's [25] review of medical apparel for elderly and disabled patients and Smith's [26] exploration of adaptive clothing needs for hemodialysis patients. Kabel et al. [23] performed qualitative focus groups of PLWD and caregivers documenting clothing barriers for PLWD during social activities. The researchers found that there is a lack of apparel available, especially for functional, cultural, and sensory related needs.

### *Universal design process*

Mace [27] defined universal design as a process that creates products that are usable by all without having to adapt or create specialized options and designs. The universal design process ensures that products can serve the widest consumer base possible, no matter the disability [19]. The Center of Universal Design created a set of principles for universal design as a base-line that could be implemented into any industry, which include (a) equitable use, (b) flexibility, (c) simple and intuitive use, (d) perceptible information, (e) tolerance for error, (f) minimum physical effort [8,20,28].

The universal design process became popular after transitioning to barrier-free design environments and implementation of the ADA requirements for architecture and building structures to assist PLWD [20]. Throughout product design history, there have been many products developed for a medical and/or disability need that have then adapted into inclusive designs. For example, the typewriter was designed in 1843 as an aid for the blind and the Jacuzzi was originally developed to help the inventor's son with rheumatoid arthritis [29]. 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 [20]. Since then, universal design is used in several industries, including the application of solving apparel needs such as the tag-less shirt and Velcro shoes [23].

Carroll and Kincade [8] applied universal design as a framework for a study on working women with a physical disability. Among the nine women interviewed and six women focus group, the researchers found that apparel could be designed to meet various disability needs, which superseded their initial research that stated different disabilities had different apparel needs. Later, Carroll and Gross [30] conducted survey research with 117 working women living with disabilities. This study's aim was to explore the women's clothing barriers to see if their physical limitation could predict clothing barrier issues. The researchers found four distinct physical limitations including limbs and extremities, core torso, central nervous system, and intellect (hearing and visual). Each of these areas effect design, material performance and dressing, which they argue universal design could solve for all.

Universal design's aim is to include everyone and to implement products that make life easier, but this process may not always be achievable, especially for mass-produced clothing. First, consumers need to accept products that are created for any process. Second, designers need to keep in mind what consumers will socially accept but also the needs and wants of all consumers [19]. Both are difficult due to limited feedback and lack of knowledge about what a consumer may need or want.

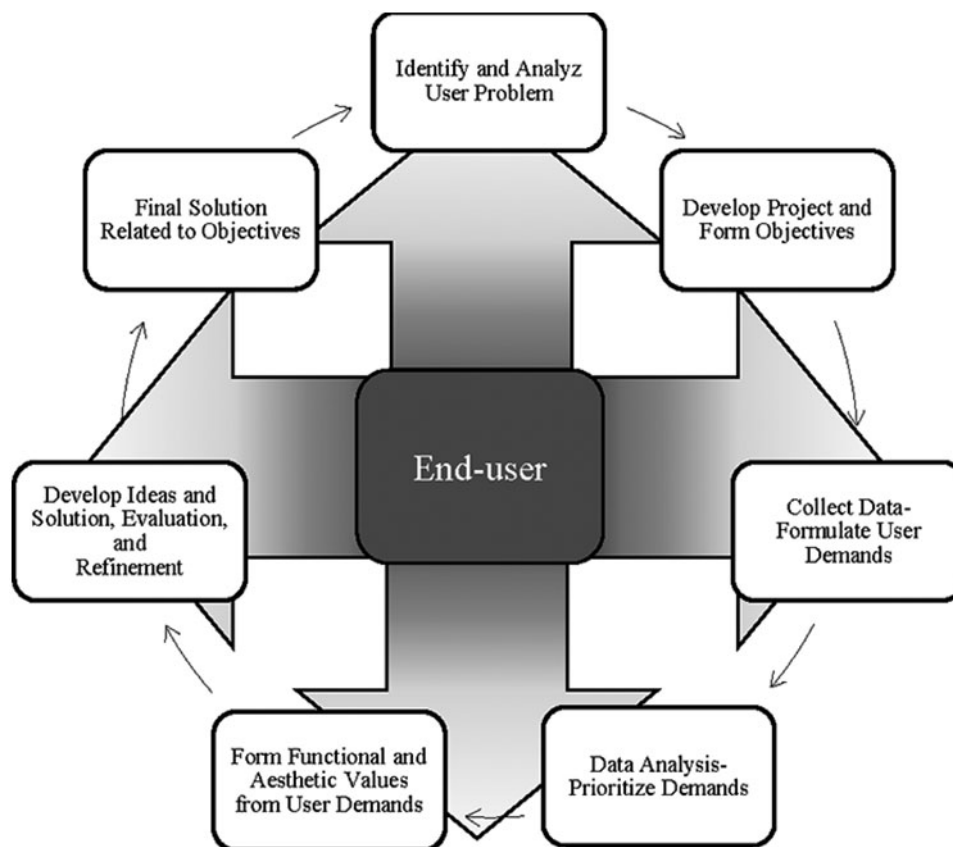


Figure 1. User-centered design process (adapted from Rosenblad-Wallin, 1985).

### User-centered design process

User-centered design began as a human factor or ergonomics engineer approach to designing products [1,31]. Norman [32] defined user-centered design as philosophically rooted in the needs and interests of the end-user, with an emphasis on making product usable and understandable. Rosenblad-Wallin [1] used this term when discussing apparel design that begins with the user's needs and wants related to their functional and aesthetic values.

The user-centered design model was constructed for systematic product design and development focusing on user demands and situation with the end-user in mind [1]. The design framework developed specific steps to design functional clothing with aesthetic appeal that include the following steps [1], illustrated in Figure 1.

Research using the user-centered design process for apparel is limited, but there is a movement in expanding this research area. User-centered design has been applied to the creation of hospital gowns [33], breastfeeding friendly apparel [34], and uniforms [12]. Thoren [35] conducted a study utilized the user-centered design process and interviewed 65 participants living with a disability and found that their requirements for dress depends on their disability, which includes: fit, function, shopping, and service in-store. The researcher emphasized function and aesthetic are both important considerations needing to be balanced.

### Research gap and questions

While a standard in the fashion industry, the traditional design process is used to create mass-produced apparel products and is not a viable option for every consumer [36,37]. Though some

retail brands have started to create clothing for PLWD, the supply is not keeping up with the demand. Unfortunately, the apparel industry has fallen short in providing functional and aesthetically pleasing clothing for PLWD [12,23,38].

Currently, both the adaptive and universal design processes are used to provide more inclusivity in the design and development of apparel products. However, because of time and money many retail brands have struggled implementing these design processes for mass-produced clothing. Consequently, PLWD have difficulty finding and purchasing apparel that fit their functional needs and aesthetic wants [19], which in turn, create social barriers and additional psychological trauma [23]. The purpose of this study was to apply the user-centered design process to understand the clothing needs and wants of people on dialysis. The specific research questions for this study were as follows:

**RQ1:** To explore the users' (people undergoing dialysis) dialysis experience through the lens of apparel.

**RQ2:** To understand the experiences and feelings of people on dialysis and the clothing barriers that arise before, during, and after treatment.

## Methods

### Research design

The aim of this qualitative study was to gain a deeper understanding of apparel needs and wants of dialysis patients using the user-centered design process. Creswell and Creswell [39] note the importance of multiple data collection methods in gaining the experiences of groups of silenced voiced such as PLWD. Therefore, semi-structured in-depth interviews were employed, along with field observation.

### Case selection

Participant selection was based on purposive sampling with the inclusion of people on dialysis (both peritoneal or hemodialysis), recent kidney transplant recipients or caregivers to a person on dialysis. This method of sampling is used in selecting participants that have a range of specific experiences, roles, and socio-demographic characteristics with the phenomena being studied [40].

After approval of the university's Instructional Review Board (IRB), fifteen participants were recruited through various doctor's offices and dialysis clinics in a U.S. south-eastern city as well as on dialysis online support groups on Reddit and Facebook. All participants lived in the U.S. at the time of data collection. Participants included 11 current dialysis patients (peritoneal or hemodialysis), two recent kidney transplant recipients who previously were on dialysis, one in-clinic dialysis workers who is also a caregiver to her husband on dialysis, and one caregiver to her husband on dialysis. Various participants were recruited to allow for an array of perspectives regarding apparel needs and wants as well as dialysis issues. The participants ranged in age from 30 to 66, with 11 females and four males. Table 1 gives the demographic characteristics of the study's participants.

### Data collection

Once initial contact from the participant, in-person or phone interviews were scheduled at the participant's convenience during March 2017. The duration of interviews ranged from 30 to 105 min. Before the interviews began, each participant gave informed consent along with an introduction of demographic questions and general rapport building. Each interview followed a similar semi-structured format following the user-centered design process with the goal of discovering personal experiences with dialysis, apparel use-situations and demands related to apparel. Specifically, the constructs the interview instrument followed for all participants were apparel use-situations, apparel use-demands, and user's apparel wants and needs.

First, questions began with their experience, feelings, or observation about dialysis. Participants were asked about the types of clothing worn they wear or their family member wears while undergoing dialysis and in their other daily activities. Next, questions were asked to determine participants' functional needs and aesthetic wants for their apparel or their family members. Further, participants were asked to describe a time when their or family members' apparel did not work with dialysis treatment. Individual stories allowed for personal and unique information, along with in-depth data collection of individual experiences. Finally, questions regarding their ideal apparel and design inputs were explored. Participants were asked to describe their ideal outfit for dialysis and one for their daily activities along with their personal style and relationship to fashion. Participants that were caregivers or clinic worker discussed their close observation of people they care for on dialysis.

In addition to semi-structured interviews, field observation was employed. Further, to understand the use-situation of a dialysis clinic and creating context, the researcher toured two dialysis clinics, which was not the same clinics all participants visited. Due to HIPPA (Health Insurance Portability and Accountability Act), observations were not allowed during operating hours, while patients were in treatment, however, observation of the waiting area and a tour of the facilities after patients left was conducted. Observation data helped to describe a social setting and its people [41] adding to the analysis of interview data.

Table 1. Demographic Characteristics of Participants.

Participant <sup>a</sup>	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	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	Owens 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

<sup>a</sup>All Participants' names are pseudo names.



## Data analysis

After the data were collected from the participant interviews, the recorded audio was transcribed by Wordsworth Typing and Transcription. Data from interviews, transcript text, and observations were coded and interpreted through the concepts in the research questions. Following McCracken's [42] method, a detailed analysis was used that moved from a specific to a more general process, in which the researchers were fully immersed in the data to find details and then move on to more generalized heuristic observations. The researchers 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 categories, which were then broken into smaller themes and sub-themes [35]. Throughout the data analysis process, the researchers confirmed 100% verbal agreement.

In addition, the following validation strategies were employed as Johnson [43] recommends for qualitative rigor. First, low-inference descriptors were used to allow the participant to detail their thoughts and feeling without the researcher taking out of context. Second, triangulation of themes and categories were validated through the two research at the times of data collection, data analysis, and interpretation. Finally, method triangulation of field observation and interviews allowed a holistic perspective of the participants and their experience.

## Findings

The findings of the holistic data analysis resulted in three theme categories, which were, (a) dialysis treatment, (b) challenges of dialysis, (c) dialysis clothing.

### Dialysis treatment

In exploring the experiences and feelings of people on dialysis, a better understanding of dialysis treatment was uncovered, which one participant described as "an evil path that I'm walking down." Regardless of time on dialysis, participants' or caregivers' experiences and feelings were consistent and echoed from previous research on dialysis lived experiences [1,6,7]. This understanding aligns with the first step of the user-centered design process, where the user problem is identified and analysed [13]. Further analysis of the theme category revealed three themes based on the different dialysis treatments; (a) in-clinic hemodialysis as "you have no control, (b) at-home hemodialysis as "I have more of my lift back," and (c) peritoneal dialysis as "the daily monotony." At-home hemodialysis and peritoneal dialysis are both conducted in the patient's home, while in-clinic hemodialysis is performed in a dialysis medical centre or hospital.

#### In-clinic hemodialysis as "you have no control"

In-clinic hemodialysis was described as "depressing," and "harsh" on the body, and a "loss of independence." Catherine described her in-clinic experience as "very uncomfortable... and it brings in some depression." Ann, a 34-year-old caregiver for her husband on hemodialysis, discussed how the "darker" colours worn by patients and the colour scheme of the clinic might be depressing to the patients. Andrea, a 53-year-old hemodialysis patient of 16 years, started in-clinic, and then went to at-home hemodialysis explains further.

**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.

During field observation at two dialysis clinics, researchers noticed each environment had a similar theme of tinted windows, chilly temperatures, unwelcoming chemical solution aromas, and generic furniture. Even the artwork displayed is sterile and austere. While some clinics are newer with soft, high-quality leather chairs, wood floors, and soft lighting, the two clinics toured by the researchers had not been remodelled in decades, frozen in dated colours with aging artwork and furniture. Each clinic ranged in physical size of space, but the use of bland colours, large chairs, and the dark windows made each appear smaller. The emphasis on being a medical clinic created a melancholy atmosphere.

#### At-home hemodialysis as "I have more of my life back"

At-home hemodialysis was described as more "relaxing" and having more "freedom" when compared to in-clinic hemodialysis. At-home hemodialysis is "easier on your body," Linda, a 66-year-old caregiver and in-clinic dietician worker said. 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. Further Jennifer states.

**Jennifer:** 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.

At-home hemodialysis allows patients an alternative to the in-clinic setting, which allows them more "independence." Sarah compared her in-clinic experience, as "when you lose your independence" to her at-home hemodialysis experience as "things are getting better." Phillip, who owns a travel agency, seemed 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.

#### Peritoneal dialysis as "daily monotony"

Peritoneal dialysis (PD), by far, was described as "felt totally normal." Peritoneal dialysis does not filter the blood, and performed daily, usually at night, so any fluid build-up 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 (in-clinic dialysis) is not something I enjoy. Whereas when I did PD at home, I didn't feel this way at all. I felt totally normal.

## Challenges of dialysis

Further exploration of participants' feelings and experiences with dialysis treatment uncovered two themes, which continue to aid in the problem analysis of the user-centered design process [13]. Challenges of dialysis were described in the following two themes; (a) physical feelings as "the desire just to rip out the

needles and run,” and (b) emotional feelings as “one huge roller coaster ride.”

### *Physical feelings as “the desire just to rip out the needles and run”*

Regardless of treatment method, the physical feelings that dialysis evokes was similar for all participants interviewed. While some had varying 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. 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.”

**Sarah:** In-centre and at home, the one thing that hasn’t changed for me in 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.

*Extreme temperature sensitivity as “I couldn’t stop shivering and I almost shock 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 varied 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 centres are purposely kept cold for “infection control” 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 (patients) coldness.

These clinics are so cold in fact that even while observing on a cold day in February, the facility still ran the air-conditioning. In addition, windows are tinted black, so even the warm sunlight is not allowed in the clinic. Linda described how her in-clinic patients would wear hats and gloves to keep warm. Stacy, a 54-year-old dialysis patient of three 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 received dialysis at home with the ability to control their environment, feel the extreme cold. Ann stated that her late husband, “during the treatments he would get very cold, and he would get under the covers in bed.” Ashley, a 58-year-old hemodialysis patient, dialyzes at home and still has extreme temperature sensitivity of being cold though running the heat. Sarah experiences not only feelings of cold but also feelings of being hot, during her at-home treatment.

**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 can’t stop shivering and I almost shook my needle out.

*Immobilized as “trapped in this chair.”* Most participants, no matter the type of treatment, felt frustration from limited limb mobility and being “strapped” to a machine. David described the most difficult part of his treatment as “not being able to get up and move around.” Others such as Andrea felt “fidgety.” Lauren, a 30-year-old hemodialysis patient of five years, described her in-

clinic time as being “strapped to a dialysis machine for four hours three days a week,” which many participants described time dragging away. Sarah detailed a situation with her arm access site mobility.

**Sarah:** The best way I can explain it is being tethered and not being able to move (...) I have to keep my hand (still) I can’t. 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 three 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 appeared to come from the type of treatment, other medical issues, and the amount of fluid “pulled off” 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. 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 most go straight home to bed. Sarah explained her feelings of being “worn out.”

**Sarah:** In-centre wore me out worse than in home. In-centre I would lose the whole day, because I would be so worn out. I would be blessed to get home and I would just crawl to bed. (...) It was crazy.”

### *Emotional feelings as “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 “(I) didn’t think I could do dialysis.” A “roller coaster of emotions” was continually used to explain the highs and lows of 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.

*Goodbye to the usual as “I went through the grief process.”* Patients on dialysis appeared to go through a grief process. Some patients only felt grief at the beginning, but for others the feeling was recurring. Along with the grief process, there was the omnipresent feelings of seclusion, depression, anxiety, and anti-social feelings. Ashley vividly described.

**Ashley:** I went through the grief process because it’s like you lose the 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.

*Fighting the battle as “I hate it with everything in me.”* The need to go to dialysis, and carry on as “normal” as possible appeared 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 often questions why she does dialysis and later stated, “you do it because you want to keep living, so you just do it.” Even though it is often

described as “torture,” people on dialysis continue and fight their daily battles. Sarah described the feeling as a “fight.”

**Sarah:** I hate it with everything in me but I fight it every time I get on. I just fight. 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. 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 (...) You gotta fight because people love you.

*Finding hope as “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 how she tries to have a good attitude and when she feels depressed, she “shakes it off.” “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. Many were grateful for their support team. Ashley 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. I feel really blessed.

### Clothing barriers

After identifying and examining the treatment challenges for people on dialysis, apparel functional needs and aesthetic wants were explored. Following the user-centered design process [13], formulation of apparel for people on dialysis was needed. In this initial formulation, specific dialysis challenges brought about clothing barriers and therefore, giving insight to design considerations when developing apparel for people on dialysis.

Dialysis treatment is challenging and therefore barriers to wearing mainstream clothing. All participants described the “dialysis uniform.” Many participants referenced their dialysis outfits and day-to-day outfits as most would not interchange the two. 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:** They (people on dialysis) wear the same thing almost every time, and usually a lot of times it was sweatpants, comfy pants, very loose-fitting clothes, t-shirts, things like that.

While discussing the dialysis uniform, four smaller themes or barriers of dialysis were identified; (a) the access site as “a big snake on your arm,” (b) the blood pressure cuff as “disrob(ing) to put the cuff on,” (c) the staining as “my clothes can get ruined,” and (d) the weight fluctuation as “taking my body shape into strange places.”

*The access site as “a big snake on your arm.”* The location and type of access site for patients effected their clothing choices, not only for dialysis, but also for their day-to-day lives. Access site locations ranged for participants, which included: upper and lower arm access (fistulas and grafts), groin catheters, chest catheters, and PD stomach catheters. The access site locations can be “exposing” and “embarrassing” for many participants. Ashley was continually embarrassed 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. 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 had 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).” 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 if 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 of the access site is of the utmost 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 wood shop, he needed a long sleeve shirt and bandages to protect his arm. 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. Sarah described her access site situation.

**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. 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 (being touched), if at all possible, because then you have to explain yourself.

The ability to conceal the access site was a concern for most participants. 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 explained her feelings of “embarrassment,” and how she disliked when strangers gave her “pity.” Some participants, such as Sarah were thankful to have an upper arm access site, because they can easily hide their access site.

**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. I don’t want anyone to approach me or ask me any questions.

*Blood pressure cuff as “disrob(ing) to put the cuff on.”* The challenges involved with blood pressure cuff issue is that one arm has the access site and the other has a blood pressure cuff throughout the duration of treatment, which leads to the inability of wearing thick fabrics, long sleeves and limits mobility. 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 (accurate 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 sweat-shirt but it's too thick to (put) the blood pressure (cuff) thing around," so she had to take them off and "freeze" during treatment. Linda describe her husbands frustration.

**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 (...) Like (if) someone came in with a heavy sweatshirt, you would probably have to disrobe that to put the cuff on.

*Staining as "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 the best colors to wear during 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 issues 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.

*Weight fluctuation as "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 thin in her arms and legs. 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 24h they wouldn't spin anymore." This was due to the constant changes in fluid retention from dialysis treatments. David described his experience with bloating.

**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. It's kind of like having a beer belly.

## Conclusions

The user-centered design process is a valuable tool when designing and developing apparel or other products for PLWD, because this process has a mechanism to include the user's feelings, experiences, and opinions. To fill the gap, this study qualitatively interviewed 15 participants undergoing dialysis or caregivers. The findings of this research can be used to help integrate the user in creating apparel that meets the functional needs and aesthetic wants of people undergoing dialysis.

The study's findings revealed three theme categories (a) dialysis treatment, (b) challenges of dialysis, (c) clothing barriers and design considerations, therefore giving voice to an under-served population of apparel consumers. As expressed by the study's participants regardless of time on dialysis, there are limited apparel options that meet the needs and wants of people on dialysis with some participants feeling overlooked by the fashion industry. As of 2016, there were 661 000 U.S. residents in kidney failure, which is expected to increase [10]. Some retail brands have started to design apparel more inclusively, with a more diverse consumer in mind [34]. Apparel brands need to move beyond just adapting their existing apparel products and designing with an array of PLWD clothing needs and wants [38].

The findings of this study have significant contributions and implications for academic researchers, industry professionals, and educators. First, this study was able to support and expand on Rosenblad-Wallin's [1] user-centered design process. Originally, the design process was utilized in the areas of ergonomics and engineering. This research helps to expand the application to apparel, filling the gap of research in apparel for PLWD and act as a catalyst for other researchers. As the findings show, participants illustrate a shared experience around dialysis treatment and the resulting challenges. Further, the finding suggests design considerations that may alleviate their apparel challenges and barriers with apparel products and features. Academic researchers in the area of textile and polymer sciences could create polymers and fibres that hold in heat and have a soft hand feel. Collaborations between textile science and designer researchers may be able to create apparel for people on dialysis, for example a textile sleeve

to replace the blood pressure cuff to lessen that discomfort of dialysis. With the continued feedback from the end user by applying the user-centered design process, successful products could come to market.

Second, industry professionals in both the fashion industry and medical area may incorporate the study's findings to not only develop new apparel products for people undergoing dialysis, but also in the preparation on the clinic's environment or even patient care. As the findings describe, people undergoing dialysis have overwhelming physical and emotional responses to their diagnoses and treatment, which builds on past research in quality of life [4] and altered sense of self [2]. This study's aim was to understand the apparel needs and wants of people on dialysis, but the findings also extend to a supporting and nurturing environment. Dialysis clinics may want to consider designing a more appealing and comforting interior treatment space, specifically applying appealing colours and warm materials.

In addition, both design researchers and industry professionals should include people undergoing dialysis and other PLWD when creating apparel and developing retail assortments. This design inclusion should go beyond the Current apparel for PLWD that is adaptively designed for a physical disability or impairment (e.g., someone in the seated position or using medical devices) [38]. These apparel options are so focused on functionality but need to be aesthetically pleasing [23]. Though the findings give design consideration for people undergoing dialysis, they could also be applied to other PLWD. Many of the design considerations are more on a psychological level that could be applied to many different PLWD to create beautiful and inspiring apparel.

Finally, the research findings can be utilized by educators as a pedagogical catalyst for developing design curricula utilizing both the user-centered design process and PLWD. At design schools and in other higher education departments of apparel design, students are trained in women's, men's and children's wear illustration, patternmaking, and construction. Non-mainstream consumers are rarely discussed, leading to students not creating portfolios and design ideas for PLWD. However, design educators could apply the user-centered design process to solve various design problems for various under-served populations, including PLWD. This would empower young designers with the design knowledge of how to incorporate a diverse consumers' needs and wants.

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