DESIGNING MEDICAL DEVICES FOR HEALING INTERACTIONS

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DESIGNING MEDICAL DEVICES FOR HEALING INTERACTIONS

A DIALYSIS CASE STUDY

A thesis submitted to the School of Design, Carnegie Mellon University, for the degree of Master of Design in Interaction Design.

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ABSTRACT

The purpose of this research is to explore the interactions between patients and life-saving medical devices, to understand how the design of these machines can be improved to promote wellness and provide a better quality of life. Life-saving medical devices such as dialysis machines, heart pumps, and artificial lungs are amazing pieces of technology that perform the incredible function of sustaining and extending life. However, aside from meeting the patient's medical needs, it is also important to consider how interactions with these devices impact a patient's psychological well-being and overall quality of life.

One of the key insights that came from my research was the idea that complex, life-sustaining medical devices may unintentionally contribute to a patient's feelings of being out of control of not only their body but also their life. For many people this can lead to depression, despite the fact that their physical medical condition is being successfully treated. As a result, I explored a wearable design concept for a patient-facing dashboard, which would help to alleviate some of these effects by (1) communicating to patients what is happening physically within their bodies, (2) promoting a sense of ownership over their bodies and their treatment, and (3) inspiring a feeling of control over their treatment outcomes and their lives.

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PROJECT DEFINITION

The purpose of this project was to explore how people perceive and interact with medical devices. My goal was to understand the role that these devices play in not only treating a patient's medical conditions, but also how they impact their psychological well-being and quality of life over a longer period of time.

01 PROJECT DEFINITION

MY MOTIVATION AND BACKGROUND

The motivation for this project came from my background and experiences as a former biomedical engineer. While working on different medical devices such as heart pumps and oxygenators, my co-workers and I were constantly motivated by the idea of saving peoples' lives. We wanted to rescue people from the brink of death and give them another chance at life. We wanted to find ways to push the limits of the technology to save more people and treat more diseases. The sense of camaraderie not only between the engineers, but also the warehouse workers, the quality control experts, the marketing specialists, and even the accountants - was inspiring. We were all working together towards this noble goal, and we felt great about the way we were helping society.

However, the day-to-day realities of the job were less idyllic. Our focus was less on saving a "person," and more on saving an organ or fixing a disease. As time wore on, the concept of these lives that we were saving became very abstract, and the only

thing tangible to us was the machinery that we worked on and the gallons of pig and cow blood that we used for testing. This mindset could not be more evident than in the daily emails that we received from our clinical representatives who traveled to be on site in the operating rooms. Through their obscure medical acronyms and abbreviations, they would tell the story of a "male, age 76" who suffered a major heart attack, and was rushed to the hospital for an emergency intervention. Oftentimes the rep would excitedly share how the doctor was "thrilled" with our heart assist device and its success in restoring blood flow in the body, adding as only a minor footnote that the patient ultimately "expired" from other complications.

There were two turning points for me during my experiences as a biomedical engineer. The first was seeing an exhibit created by an artist-friend to express the traumatic emotional experience of being hospitalized as a child. She created a larger than life installation piece consisting of IV tubing draping downward from the ceiling, to symbolize the fear and pain from her childhood memories. As someone who was highly desensitized to the sight of medical equipment, I was confused and looked around quizzically as I stepped into her exhibit. To me, it seemed to represent healing, and I was shocked and appalled at my own inadvertent insensitivity when I realized these objects took on a deeper meaning of pain and suffering in the eyes of the average layperson.

The second turning point was the day I looked into the eyes of a man during his last waking moments before he died following an "otherwise successful" heart surgery. It was one of the few times I had the opportunity to observe a live surgery with our product in a hospital, and I was excited to see the heart assist device that I had worked on for so long in action. Before he was even wheeled in, the room was already bustling with nurses, technicians, and doctors busily setting up, as well as a slew of scrub-clad onlookers who had enthusiastically gathered for the opportunity to observe the procedure. As the grandfatherly-looking man was brought in on a gurney, he nervously tried to speak to anyone nearby, maybe hoping for some last bit of reassurance. The nurses were

distracted with their preparation duties, the anesthesiologist impatiently began the process of putting him under, and all the while the rest of us chatted away excitedly amongst ourselves. I would later find out that those were the man's last conscious moments before he died later that night, and rather than showing concern, reverence, or compassion for him, we were too wrapped up in our excitement over this machine that would ultimately save his heart but not his life.

These experiences led me to the revelation that treating a disease only takes you so far if you ignore the person attached to that disease. While it is necessary and important to develop medical technology that saves lives, it is also important to consider the quality of life and the emotional well-being of the person you are trying to help.

01 PROJECT DEFINITION

PROJECT SCOPE

In order to begin to explore the relationships between patients and medical devices, I narrowed the scope of my research to focus on medical devices that met three key criteria:

LIFE-SUSTAINING

Life-sustaining devices place patients in the vulnerable position of depending on a machine to survive. If the machine malfunctions, if supplies run out, or if power is lost for an extended period of time, the patient's life would be in grave danger.

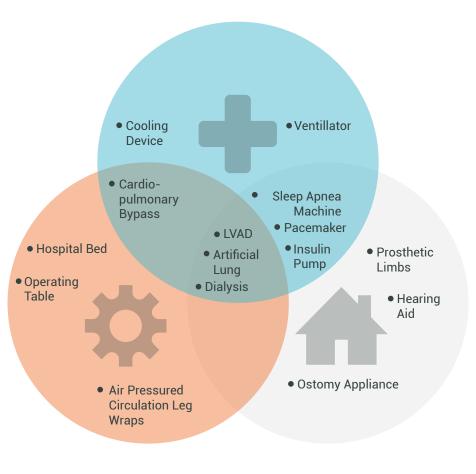
MECHANICALLY COMPLEX

Mechanically complex devices have a prominent physical presence, they require more advanced mental models to understand how they work, and they often are more difficult to learn to operate.

HOME OR CLINIC USE

Devices that are (or have the future potential to be) used in a home or clinic setting, as opposed to only in the ICU, play a more prominent role in patients' everyday lives. Patients must incorporate their use into their everyday routine, and the devices can even become part of their identity. If they must be integrated into the home environment, their presence has an impact on other family members as well.

The devices that met this criteria included various types of artificial organs or organ-support devices: heart assist devices, artificial lungs and oxygenators, and dialysis machines. Out of these devices, I chose to focus on dialysis machines as my main case study.



TYPES OF MEDICAL DEVICES IN SCOPE

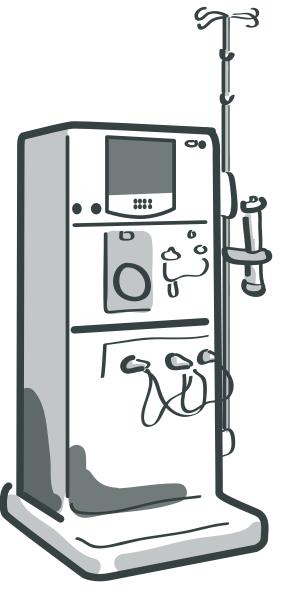
01 PROJECT DEFINITION

WHY DIALYSIS

In the medical device community, dialysis is regarded as a pinnacle of success. Unlike other artificial organ devices like heart assist devices and artificial lungs that are highly invasive and can only be used temporarily, dialysis can be used safely for years or even decades for patients who have irreversible kidney failure.

However from the patient's point of view, they must face a lifetime of relying of a machine to survive, spending many hours per week in treatment sessions, and enduring countless medical appointments and interventions. A typical dialysis treatment regimen consists of treatment sessions lasting around four hours long, at least three times per week, for the rest of the patient's life. Depression is a huge issue that dialysis patients face, and some patients even elect to forgo or discontinue treatment because they feel that their lives are not worth living.

To me, this is a perfect example of a medical device that treats the disease but neglects the overall well-being of the person. Furthermore, since the medical community aspires to achieve this level of technological success with other artificial organ devices, any insights from this study would be applicable to those devices in the future as well.



A TYPICAL DIALYSIS MACHINE

02

PRIOR WORK

I conducted a literature review in order to gain a broader understanding of relationships between patients and medical devices. I looked at psychological stress factors that patients face, various healthcare environments and how they may cause stress, as well as how medical devices themselves may cause stress. Finally, I explored existing design concepts aimed at addressing patient quality of life through improved medical device design.

INTRODUCTION

People who suffer from critical and chronic diseases, such as dialysis patients, face an immeasurable level of stress. In addition to the physical toils and symptoms of the illness and fears about their own mortality, the environment of the hospital or dialysis clinic may be a source of stress in itself.^{18,7} There is little privacy, patients have limited control over their surroundings, and alarms are constantly going off, making it difficult to relax and focus on healing.⁸

For this reason, there has recently been a push in the medical device industry to develop devices for in-home use when possible. This is an exciting development, because by enabling people to receive treatment in their homes, it reduces many of the stress factors specific to the hospital or clinic environment. Patients regain their privacy, control of their environments, and have a sense of ownership and authority over their treatment. It also gives people back their time, and allows them to lead more normal lives. However, medical devices themselves remain a less obvious source of stress for patients. In addition to their intimidating appearance, a patient's lack of understanding about how they work can contribute to their feeling of not being in control. For patients who have been trained to operate medical devices at home, they are faced with the additional challenge of integrating them into their homes and lives.

Thus far, these issues have mainly been addressed through improved patient education and training initiatives, or through the service design of in-home medical care. The concept of reducing the psychological stress on a patient through improved medical device design remains an opportunity to be explored. This approach would have the added advantage of benefiting patients in hospital, clinic, and home environments alike.

STRESS IN CHRONIC ILLNESS

Stress is known to affect the body in physiological ways, in addition to causing psychological distress.⁶ For patients who are faced with critical and chronic illnesses, their ability to cope with stress may be a key factor impacting their ability to recover or respond to their treatment. According to Fortune et. al., "The process of coping involves cognitive appraisal of the threat, followed subsequently by attempts to either remove or mitigate the effects of that threat." ⁴

In a study aimed at exploring the correlation between stress and coping strategies and medical outcomes in patients with psoriasis, Fortune identifies four types of coping mechanisms that patients employ:

PROBLEM-FOCUSED COPING

In problem-focused coping, patients focus on addressing the problem at hand in practical ways in an attempt to eliminate the source of the stress.

AVOIDANCE COPING

In avoidance coping, patients try to ignore the problem in order to avoid facing unpleasant thoughts or feelings. This method is strongly associated with high anxiety levels.

EMOTION-FOCUSED COPING

Emotion-focused coping focuses on mitigating unpleasant emotions, rather than addressing the actual underlying problem.

DISTANCING / REAPPRAISAL

Distancing / reappraisal involves changing the way one thinks about the problem, by changing their goals or values.

When facing an illness that they can't control, distancing/reappraisal was found to be a helpful way for patients to begin to accept their situation and establish a "new normal." Avoidance coping and emotion-focused coping were found to be less effective, and associated with higher levels of anxiety.⁴

HEALTHCARE ENVIRONMENTS AS STRESSORS

Like other chronically ill patients, dialysis patients may receive care in a variety of environments throughout the course of their illness. A typical treatment routine may involve going to a dialysis center three times per week. However, complications are commonplace and patients can often end up in the hospital to address more serious conditions.

THE HOSPITAL

For critically ill patients, the intensive care unit of the hospital is a particularly stressful environment. In a questionnaire survey given to critical care unit patients by Hweidi et. al., several stressors were identified.7 Having tubes in one's nose or mouth gives the patient a sense of immobility, and limits their ability to eat and communicate. Physical discomfort, including being in pain or being thirsty, was an issue. In addition, the psychological effects of the environment were bothersome. The presence of strange machinery made the patients uncomfortable, and hearing buzzers and alarms from the machines disturbed them. A combination of these factors led

to an inability to sleep, and patients later recounted that they disliked not being in control of themselves.

A study by Johansson et. al. was performed in 2012 to specifically investigate soundbased stressors in intensive care units.⁸ Sounds, such as alarms coming from machinery, were found to have a positive effect if the nurses explained where they came from and what the meant. In general it was important for the patient to feel like they were in control, and aware of what was happening around them. If patients had previously stayed in an ICU, they were more familiar with the sounds, and less bothered by them. However, for certain patients, noises were a significant source of stress. Noise induced stress occurs when a patient is "unable to ignore, block out, or otherwise cope with the unwanted sounds, or is able to do so only at a cost." For many patients the sounds interfered with sleep, which is essential for recovery. Patients cited the unpredictable shifts between silence and disturbing sounds as a key stress factor. Patients were also bothered by sounds of

pain or moaning coming from other patients in the unit, especially if they shared a room. Being able to hear but not see, and therefore not knowing what was happening to the person, was distressing and bothersome.

Patients often rely on the hospital care staff or visiting family members to identify and remedy sources of stress during their stay in the ICU. In one study by Novaes et. al., the perception of stressors by patients, nurses, and family members was compared and evaluated.¹⁸ Although each group generally identified the same list of stressors, the relative importance of each source of stress differed between groups. In general, the care team and family overestimated the patient's overall stress level compared to what the patient reported. However, the care team tended to underestimate the stress associated with having no control over one's own body, being unable to move one's hands or arms, and not knowing when things will be done. Since the care team is responsible for administering the care and treatment, they tend to become unaware of the patient's loss of autonomy and feeling

of not being in control. The family tended to overestimate the importance of their own presence at the patient's bedside. Patients reported that they were much more concerned with their physical discomfort than issues such as loneliness when they were in great pain and fighting for their lives.

THE DIALYSIS CLINIC

While the environment of the dialysis clinic may be less acutely stressful than that of the hospital (though some issues such as frequent alarm sounds may still be present), the fact that the patient is required to travel to the clinic for frequent treatments creates a burden in and of itself.²² Dialysis is a time-consuming treatment that must be administered frequently in order to adequately take over the function of the patient's kidneys. Typically, patients must go to a dialysis clinic 3-4 times per week for treatment sessions lasting around four hours each. This is extremely disruptive to the patient's life, interrupting their schedule, making travel logistically difficult or infeasible, and reducing the patient's autonomy over their life.

THE SHIFT TO HOME CARE

For certain types of chronically ill patients, in-home care is being explored as an alternative to long-term treatment in a hospital or clinic-based setting.¹ Although this option is not available to all patients, especially if their condition is unstable, it offers an exciting solution to many of the environmental stressors and lifestyle disruptions that the hospital environment presents. Patients have the opportunity to regain their privacy, control of the environment, and can live a more normal lifestyle. Due to patients' improved psychological well-being, some studies have reported that patients who receive care at home have improved medical outcomes compared to those who receive treatment in a hospital.^{20,21}

In-home care is becoming an increasingly popular alternative for patients on dialysis, in particular.²² For patients who are physically and mentally capable, administering their own dialysis at home offers an opportunity to take control over this huge disruption to their lives. Patients may administer dialysis in their sleep, which not only gives them back their lives during the day, but it also allows them to spread out each treatment session over a longer period of time. This makes the treatments gentler and less draining, improves their medical outcomes, and helps them to feel better physically.

Although home-based care offers many advantages, it also introduces some new challenges. A study conducted by Wong et. al. on the home dialysis training experience identified several themes related to the challenges that patients face while learning to self-administer this treatment:

ANXIETY

While shifting the medical responsibility to the patient gives them greater autonomy, it can also cause anxiety. Many reported a fear of needles, and dreaded the idea of having to stick themselves with needles. They were also uncertain about the training program itself, and feared that they wouldn't be able to successfully learn the procedure. Since dialysis treatment is normally administered by "medical professionals," many patients feared that they simply did not have the qualifications needed to complete the training as laypeople.

PEER SUPPORT

During the training process, patients thought it was greatly beneficial to have peers who were undergoing the same training at the same time. They offered each other encouragement, acknowledged each other's challenges and fears, and offered reassurance that their fears and learning mistakes were normal.

CLINICIAN EMPATHY

The patient's ability to persevere through the training process was strongly impacted by the empathy and understanding shown by the clinician training them.

LEARNING WHILE ILL

Patients learning to self-administer dialysis must go through the training procedure while they are ill, making it even more difficult to learn to operate this complex medical device. Patients reported feeling exhausted and sleepy.

LEARNING STYLE

Patients had different preferences for learning the procedure. Some preferred to learn through hands-on demonstrations, while others wanted to be able to refer to written step-by-step instructions. Many patients expressed that they wanted to understand why there were doing what they were doing, rather than just memorizing the steps of the procedure.

TECHNICAL COMPETENCE

While patients initially reported anxiety over the prospect of achieving technical competence, this was not found to be an issue. Patients were able to successfully learn the procedure, and their initial fears and objections were primarily psychological.

MEDICAL DEVICES AS STRESSORS

Although the function of medical devices is to deliver therapy and enable healing, their physical form and appearance may cause stress.⁹ The visual complexity of so many tubes, wires, dials, and buttons is overwhelming. Disruptive alarms and warning lights not only disrupt sleep, but they also induce fear and reduce trust in the equipment. Many forms, such as needles, IV tubes, and tubing conduits for blood are unnatural to a layperson and invoke feelings of pain. For patients with long-term illnesses, it is dehumanizing to be continuously tethered to a device, and to know that your life depends on a piece of mechanical equipment.

Medical devices used in the home introduce additional challenges. The appearance of the equipment can look very institutional and clinical, and this makes it difficult to integrate into the home environment. Many pieces of equipment such as dialysis machines require copious supplies, which can quickly take over a room. Finding a way to store both the device and the supplies can be a challenge. Patients report that they or their families are sometimes self-conscious about having their home look like a hospital room. Additionally, pets or children may need to be kept away from the treatment room due to the need to keep the space clean for the sterile or aseptic portions of the procedure.^{22,10}

DESIGN OPPORTUNITY

Much of the work that has been done to address quality of life issues for patients with critical and chronic illnesses has focused on the shift from hospital or clinic to home-based care, and improving the service design of administering treatment at home. However, there has been relatively little focus on reducing the patient's psychological stress through the design of the medical devices themselves. Some efforts have been made to alter the physical appearance of devices that are inherently fear-inducing, such as needles. Other efforts have been made to increase patient mobility and freedom through portable and/or wearable versions of devices. However, these areas still have opportunity to be developed further, and other areas remain yet to be explored.

For devices used in the home, competency in operating the devices can be addressed by improving their usability, and industrial design can be used to better integrate the product into the environment of the patient's home. However, on a more fundamental level, the design of medical devices must take into consideration the patient's normal activities and lifestyle, so that they impose less of a burden on the patient's life. Even more importantly, the goal of medical device design should be to give the patient as much control as possible over their lives.

PHYSICAL APPEARANCE OF DEVICES

Stress-reducing syringes and needles have been developed in an effort to reduce the stress associated with needle phobia. A study by Kettwich et. al. focused on evaluating the impact of these products on needle phobia in adult and pediatric chemotherapy patients.⁹ They found that although people experience needle phobia to varying degrees, all participants felt that stress-reducing syringes and needles were beneficial and should be made available to all types of patients.

For dialysis patients, the fear of needles is one of the top anxieties that patients have prior to starting treatment. During each treatment, large needles are inserted into the patient's arm, allowing their blood to travel to the dialysis machine for cleaning via clear tubes. The sight of blood in the clear tubes can also make patients uncomfortable and stressed, especially in dialysis centers where many patients receive treatments together within sight of one another in a single room.



STRESS-REDUCING SYRINGES 9



STRESS-REDUCING NEEDLES 9



"MOBILYSIS" WEARABLE DIALYSIS CONCEPT 5



"PURIFIER" WEARABLE DIALYSIS CONCEPT ¹²

PORTABLE, WEARABLE DEVICES

Another development has been the push for wearable dialysis machines. For dialysis this technology is not yet at the point where it is feasible, but prototypes of future designs have been proposed. These devices would enable patients to receive dialysis continually throughout the day, which would greatly alleviate the highs and lows associated with extended gaps between treatment sessions. Moreover, the wearable device would allow patients to no longer be confined to their homes or tethered to a stationary piece of equipment during treatment, effectively freeing up their time.

Other types of wearable artificial organ devices, such as heart assist devices, have already been developed. The Heartmate II left ventricular assist device is an implanted heart pump with a wearable external controller and battery pack connected by a cable. This device allows patients waiting for a heart transplant to return home and go about their lives for months at a time, even if their native heart is not functional.

03

EXPLORATORY RESEARCH

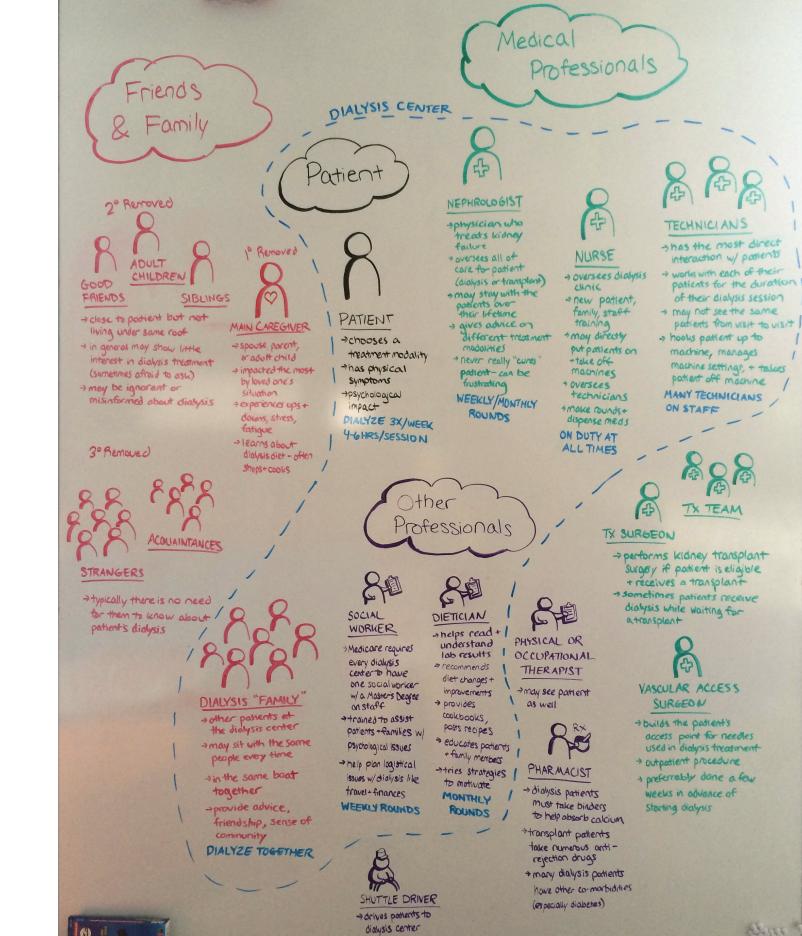
To gain a better understanding of the issues that dialysis patients face, I read case studies and conducted one-on-one in-depth interviews. I spoke with dialysis patients, nurses, and caregivers from a variety of backgrounds. This research led me to the development of four different patient personas, a journey map describing the dialysis patient experience, and insights into the complex ways that dialysis impacts a patient's quality of life.

CASE STUDIES

I began my research by reading books and case studies written for or by dialysis patients, in order to gain a better general understanding of their experiences. *Dialysis Without Fear: A Guide to Living Well on Dialysis for Patients and Their Families* by Daniel Offer, Marjorie Kaiz Offer and Susan Offer provided a general overview of kidney disease, dialysis treatment options, and first-hand interview transcripts with patients, family members, and professionals.¹⁹ *Arranging Your Life When Dialysis Comes Home: The Underwear Factor* by Linda Gromko and Jane McClure discussed the myriad benefits of home dialysis, and included tips for accommodating dialysis equipment and supplies in the home.⁶

STAKEHOLDER MAP

Based on the information provided in the books and case studies, I created a stakeholder map (shown at right) to summarize the numerous groups of people involved in a dialysis patient's life. It includes friends and family members, various teams of medical professionals, as well as other therapists and miscellaneous professionals with whom the patient interacts throughout the course of their treatment journey.



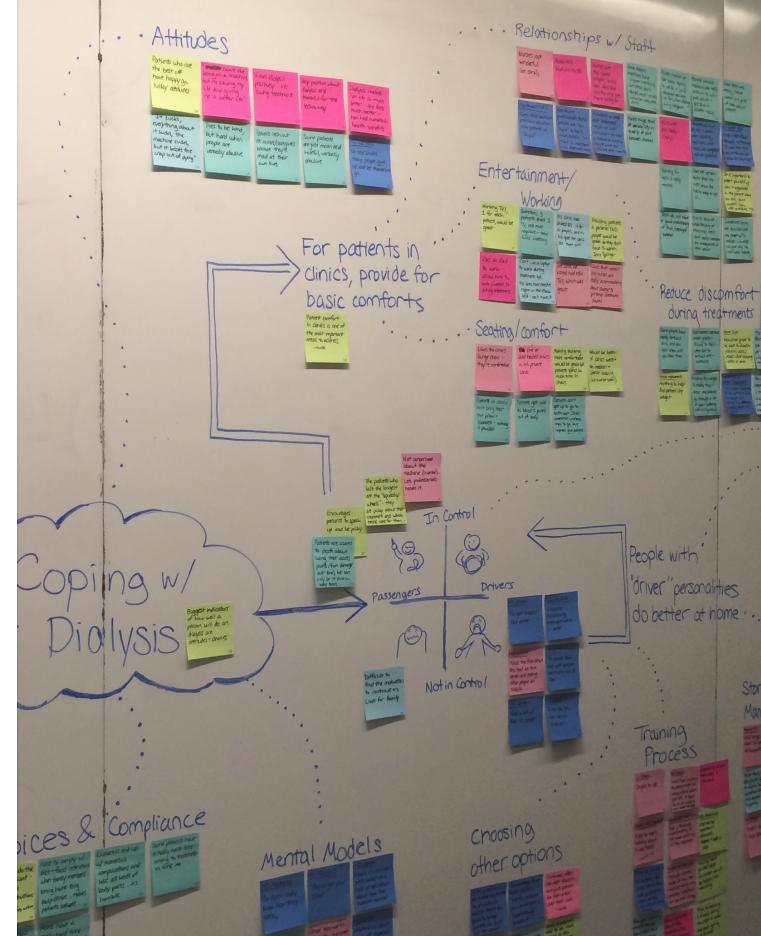
INTERVIEWS

I joined Facebook support groups and reached out through personal contacts and social media to conduct one-on-one in depth interviews with patients, caregivers, and healthcare professionals. The patients with whom I spoke varied in age, their length of time on dialysis, and the type of treatment they were receiving. Some were brand new to dialysis while others had been on dialysis for decades.

My goal was to gain a better understanding of what dialysis patients' lives are like and what sort of issues they face. I asked in-depth questions about their experiences, how they perceive and interact with the dialysis machine, how dialysis has impacted their lifestyle, as well as their ideas for improvement.

Although I focused mainly on dialysis, I was also able to speak with two former artificial lung (ECMO) patients, one former heart pump (LVAD) patient, as well as their families. While their experiences differed from those of dialysis patients because their illnesses were acute and their reliance on a machine was only temporary, many aspects of their experiences echoed similar themes.





PERSONAS

Throughout the course of these interviews, a pattern of patient personalities and coping mechanisms began to emerge. Some people had what I termed a "passenger" personality, meaning that they preferred having their dialysis treatments done in a clinic so they could relax and feel cared for. They tended to be more trusting of their care team, and felt relieved that the professionals bore the responsibility for managing their treatment.

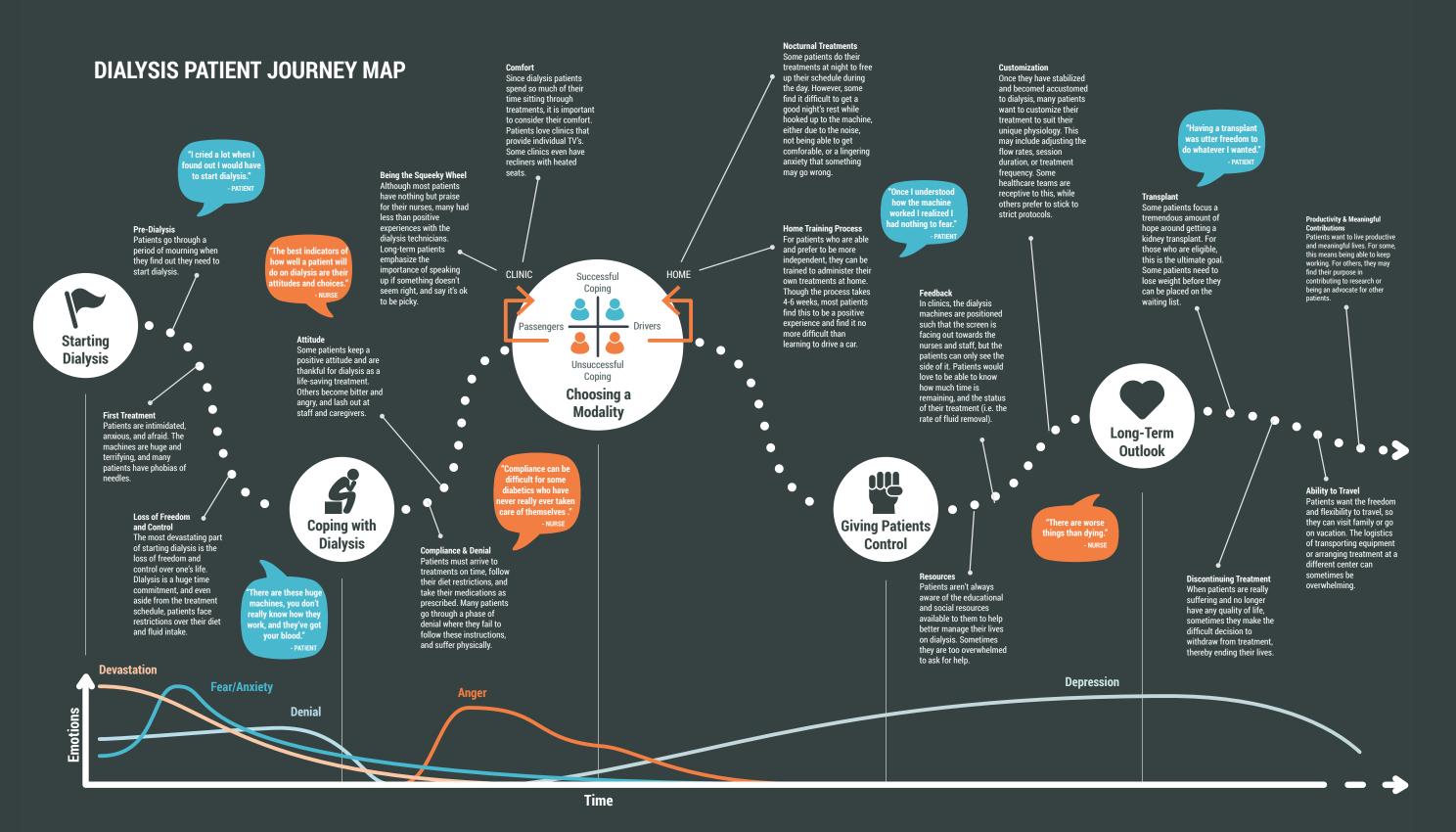
On the other hand, other patients had what I termed a "driver personality." These people had a stronger need to feel in control over their dialysis machines and their treatment. They were more likely to second guess their healthcare team or ask for further explanations. These patients tended to feel happier and more in control when they were able to be trained and equipped to administer their own treatments at home.

Either of these personality types could cope successfully or unsuccessfully with being on dialysis. Passengers who coped best tended to be the outgoing, extroverted "squeaky wheels" who didn't mind asking the dialysis nurses and technicians for exactly what they needed. The passengers who didn't cope well tended to feel that they didn't have a voice or the courage to speak up, and as a result they felt helpless over their situation and slipped into a silent depression.

The drivers coped best when they were able to achieve independence by doing dialysis at home. Drivers who were unable to do home dialysis - either because they didn't have a caregiver, due to other disabilities, or because of temporary complications tended to be the most upset and distressed.



Unsuccessful Coping



SYNTHESIS

To synthesize my findings I transcribed all of my interviews onto post-it notes, and clustered common experiences and themes. This affinity diagram ended up taking the form of a collective user experience journey map, describing the events, issues, and emotions that patients face throughout their treatment journey (shown on the previous page).

INSIGHTS

The saddest part of my research was that many patients I talked to readily admitted that at some point they had considered voluntarily discontinuing their treatment, which would mean letting themselves die. This is so ironic and disheartening, because dialysis technology is so successful in replicating the function of the human kidney, and yet the machine still imposes such a poor quality of life onto these patients that they feel their lives aren't worth living.

Going into the research, I expected to find that the main issues with the design of the device were its poor usability and the visceral emotions caused by its intimidating physical appearance. However, I discovered that patient interactions with the device are actually far more complex. The following insights describe how the design of the device directly and indirectly impacts a patient's quality of life.



LIFESTYLE RESTRICTIONS

The device indirectly imposes certain limitations on the patient's physical abilities and lifestyle. Patients must drastically alter their diet to supplement their care, the treatment schedule is a huge burden on their time, and their reliance on this machine makes travel logistically difficult. These restrictions greatly reduce the level of freedom and control that patients have over their lives, often leading to depression.



SERVICE ECOSYSTEM

The complexity of the device necessitates an entire service ecosystem of nurses, technicians, doctors, and educators who must take responsibility for operating the machine or managing the patient's treatment parameters. The people in these roles interact closely and frequently with the patient, and have a substantial impact on the overall quality of their experience. Patients tended to report having positive experiences interacting with the nurses, but oftentimes their interactions with the underpaid and overworked technicians were of lesser quality.



LEVEL OF INDEPENDENCE

Due to the complexity of the device, patients must either rely on others to receive treatment in a clinic, or they must meet numerous physical and logistical requirements in order to feasibly perform dialysis treatments at home. Even with home dialysis treatments, a fully-trained caregiver (usually a spouse) is required to be present at all times during treatments in case of emergency. In either arrangement, the patient is completely reliant on others, greatly limiting their independence and sense of autonomy.

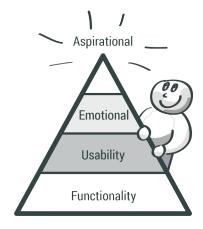
MASTERY AND KNOWLEDGE

Surprisingly, instead of being frustrated by the steep learning curve required to operate home dialysis machines, patients actually viewed the process as a positive experience. The intensive six-week training process was one of the few times that they had one-on-one attention from a nurse. Learning about the equipment and their disease made them feel empowered, like they were finally taking control over their lives. Their mastery over this medical procedure, which is normally only performed by medical professionals, gave them a sense of pride.



SUPPLIES & MAINTENANCE

The supplies required to operate the machine impose a huge logistical burden on home dialysis patients who are already struggling with a severe illness. Some devices require 20 or more boxes of fluids and disposables to be delivered per week, then carried, stored, inventoried, and disposed of in one's home. The supply inventory can take up an entire closet, or sometimes even the whole length of a wall in a spare bedroom. This makes travel especially difficult, because in additional to moving a bulky and heavy machine, supplies must be coordinated and delivered as well.



FUTURE OUTLOOK

All of these factors impact a patient's overall outlook. However, there is a difference between devices intended for short, temporary use in emergency situations, versus devices that the patient will remain on permanently. It is easier for people to cope with various stressors if they know they will be cured, or if the situation is only temporary, although the experience stays with them if it was traumatic. But for dialysis patients who will be on the device for the rest of their lives, we must consider how the overall device experience impacts their quality of life and outlook on the future.

04

GENERATIVE RESEARCH

Based on the insights I gathered from user interviews, I sketched out storyboards for some potential design concepts, and speed dated them with dialysis patients. Although the concepts themselves were simple ideas which addressed seemingly isolated issues, the feedback I received consistently pointed to the larger issue of the strained relationships between patients and their healthcare teams.

DIALYSIS PATIENT NEEDS

The insights I gained from my user interviews showed how the design of dialysis machines can impact a patient's quality of life. In order to move forward with identifying a design solution, I first created a summary of user needs to be addressed:

HEALTH

Dialysis patients want to optimize their physical health. They want effective dialysis treatments, and the ability to customize them to suit their individual needs.

TIME

Dialysis patients have many demands placed upon their time. Long treatment sessions, travel time to and from appointments, and managing logistical tasks makes dialysis feel like a part-time job.

Dialysis patients are restricted in their mobility. They can't move their arm during treatments, they are confined to a chair, and on a larger scale they are limited in their ability to travel.

PURPOSE

Dialysis must not interfere with one's ability to find meaning and purpose in life. Patients want to spend quality time with family, and for some people, maintaining the ability to work is important.

CONTROL

Dialysis patients want to be in control of their treatment and their lives, but their independence can feel limited due to their reliance on caregivers and their healthcare team. The ability to choose a treatment modality that suits their personality, as well as receiving dialysis education, can help them to regain a sense of control.

STORYBOARDS & SPEED DATING

I sketched out storyboards for three potential design concepts, and used an online survey to speed date these concepts with dialysis patients. I also asked for their feedback on the list of user needs that I had come up with.

I received a total of 22 responses, and the overwhelming consensus was that my list of user needs accurately addressed the issues they faced. Although I received a mixture of positive and negative feedback on the design concepts themselves, the responses revealed an underlying theme of tense relationships between patients and the healthcare team.

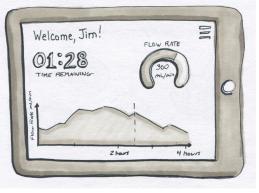
CONCEPT #1: CONTROL IN YOUR HANDS

In dialysis centers, oftentimes patients cannot physically see the screen on the dialysis machine because it's facing away from them. In this concept, dialysis machines would come with a second portable screen, like an iPad or a tablet, that patients could view to see what's happening during their treatment. It could show how much time is remaining, how much fluid will be removed over the course of the treatment, as well as their personal treatment history - things like statistics and data trends over time.

FEEDBACK

Patients responded positively to the idea of being more informed and educated about what is happening during treatments. Those who interpreted the concept as simply showing an exact replica of the main screen commented that patients probably wouldn't be able to understand the information anyway. Some also noted that they already have a habit of asking the dialysis technician to turn their machine towards them.



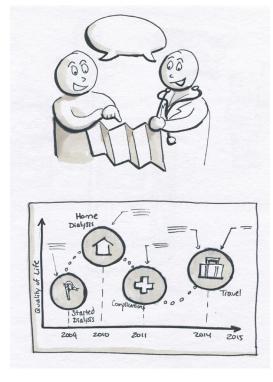


CONCEPT #2: TREATMENT ROADMAP

Medical charts don't always tell the whole story. They don't consider a patient's emotions, or other external factors impacting their quality of life. This roadmap would be a personalized story of one's dialysis history, treatment plan, and goals, created by the patient themselves. It would be more than just numbers and data. It would include past struggles, and any customizations they've made to their treatment regimen. It would also include goals, whether that's losing weight so they can get a transplant, or being able to travel so they can go on vacation or visit family. The roadmap could be either a tangible artifact or a digital tool.

FEEDBACK

Patients strongly favored the idea of having a voice in their treatment plan. However, their current relationships with their healthcare teams are so poor that they thought this information would simply be "ignored," or worse, that it would be used in a "condescending" way to "patronize" them.

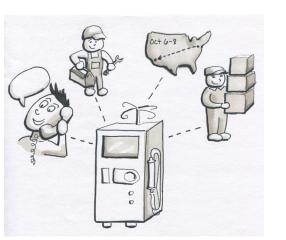


CONCEPT #3: A DIALYSIS MACHINE THAT CARES FOR ITSELF

Dialysis machines should act like guests in your home. They shouldn't leave messes all over the place, and they shouldn't rely on you to take care of them. This concept would be a service that would be paired with home dialysis machines. The service would take care of ordering dialysis supplies, scheduling routine maintenance, and arranging transportation for the machine when you want to travel. This shifts the burden of responsibility off of the patient, so they can focus on taking care of themselves.

FEEDBACK

Home dialysis users reacted positively to the idea of not having to manage supply inventories or arrange traveling logistics. However, they balked at the implementation of the concept. They said that using a service to handle these things would be just as much hassle as handling them themselves. People noted that they had a particular way of organizing and keeping inventory of their supplies, and wouldn't want to have to explain it to someone else.



Since dialysis patients must have dialysis, and need to follow orders for best health, the nurses, schedulers, and doctors sometimes **treat you like a child or slave whom they can order around** -- and who has nothing better to do -- as opposed to another adult who has a full-time job and a life.

When I was in-center everyone acted like it was a big complicated secret and that

patients were too dumb to even try understanding it. The more patients know about their treatments the greater their feeling of being part of the treatment team and responsible for their well-being.

I think [the treatment roadmap] is a good idea, but I can't imagine my care team doing anything more than just patronizing me through its use. 22

STRAINED RELATIONSHIPS

The most common theme throughout the survey responses was the strained relationships between patients and their healthcare team. Starting from the time the patient is faced with this devastating health crisis, they feel like their healthcare team is always telling them what to do (don't eat this, come to this appointment, go to these treatment sessions). Patients lose many personal freedoms, including their time, their ability to freely travel, and potentially the ability to work. Along with the loss of so many freedoms and their loss of autonomy, receiving all those orders made patients feel like they were being bossed around.

From the healthcare team's point of view, they must frequently interact with patients who are depressed and angry, who take out their frustrations on whoever is around. Furthermore, they see the consequences of poor lifestyle and health decisions on a daily basis, so it frustrates and saddens them when patients don't adhere to their diet restrictions or treatment plans.

Finally, there is tension that develops around the machine itself. Since it's such a complicated device that requires special training to operate, patients may not always understand what is happening or why the professionals are making certain decisions. This communication barrier, combined with other existing tensions, can lead to a breakdown of trust.

DEVASTATING HEALTH CRISIS LOSS OF PERSONAL **FREEDOMS PERCEPTION OF BEING ORDERED AROUND TENSIONS BETWEEN PATIENTS & TECHNICIANS** LOSS OF MUTUAL TRUST **AND RESPECT**

05

DESIGN Solution

My design solution is a wearable dashboard displayed on an armband, that makes a patient's data and status both visible and accessible to them during their treatment. On a subtler level, the armband also metaphorically communicates to the patient's healthcare team that the patient is in control of their body. The goal of this solution is to empower patients to take an active role in their treatment, increasing their sense of control over their lives.

05 DESIGN SOLUTION

0

OVERVIEW

My final design concept is a wearable armband, owned by patients, that makes their data and the status of their treatment both visible and accessible to them during treatments in clinics. This solution addresses 3 key issues:



Make data visible to patients by placing it where they can physically see it, and presenting it in a way that is intuitive.

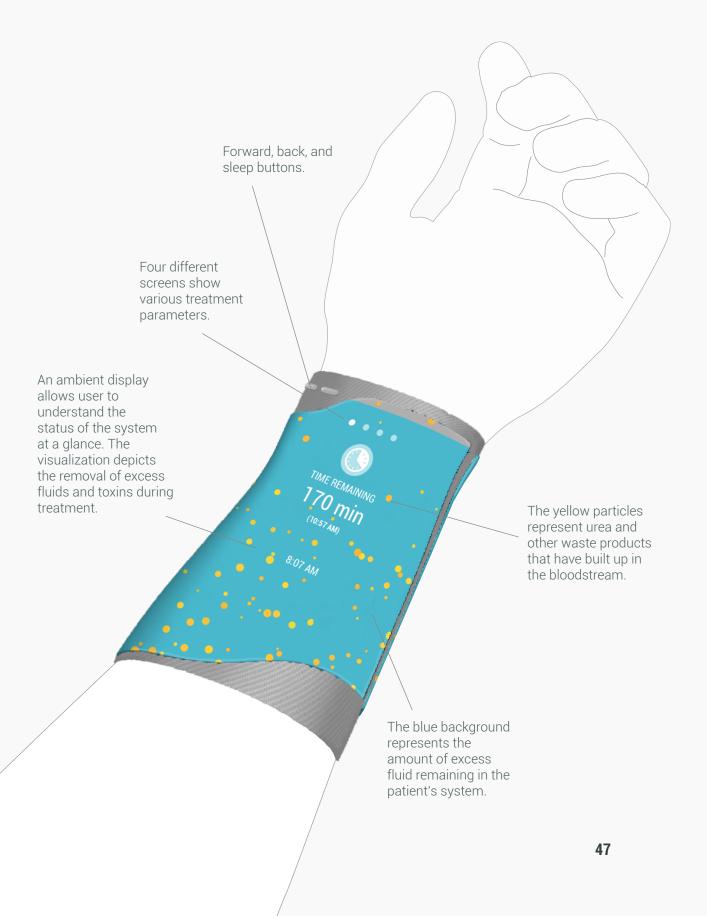
OWNERSHIP

Give patients ownership of their data to make them active participants in their treatment.



RELATIONSHIPS

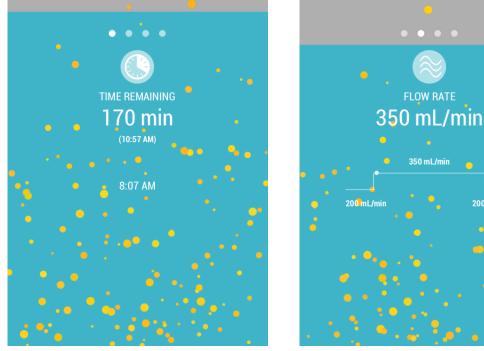
Improve relationships between patients and their health care team by metaphorically communicating that the patient is in charge of their body.



05 DESIGN SOLUTION

DATA VISUALIZATION

The dialysis dashboard externalizes the patient's current system state by using intuitive visualizations to make their information understandable. Four different screens show time, fluid volume, flow rate, and waste removal.

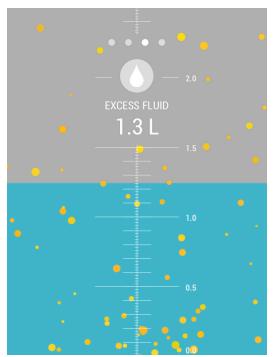


TIME REMAINING

One of the most frequent questions that dialysis patients ask during treatment is, "how much longer is this going to take?" This dashboard communicates not only the amount of time remaining, but also the variables it is dependent on.



that has accumulated in the body. The blue background area represents the volume of excess fluid remaining. The fluid level starts the top of the screen, and gradually drains to the bottom by the end of the session.



FLOW RATE

The faster the blood moves through the machine, the faster it will be cleaned. However, higher speeds (as represented by the movement of the particles) may cause the patient to experience painful cramping. This visualization shows flow rate settings throughout the course of the session.

UREA CONCENTRATION 29.1 mg/dL Start 50 mg/mL

WASTE REMVAL

The key goal of dialysis treatment is to remove excess waste products that have built up in the body. The yellow particles represent the waste products in the bloodstream. These particles will gradually disappear throughout the course of the treatment session.

05 DESIGN SOLUTION

DESIGN DESCRIPTION

The dialysis dashboard is a wearable armband that makes the patient's data and status both visible and accessible to them during their treatment. An ambient data visualization allows the patient to understand the status of their treatment at a glance. The dashboard is intended mainly for use in dialysis clinics, and will be most beneficial for both "passenger" and "driver" patients who have not found other successful coping mechanisms.

DATA VISIBILITY

The armband makes data physically visible to patients. In clinics, the machines are typically physically turned outward, facing the nurses and technicians, which means that patients can't see the screen and therefore don't know what's happening to them. This exacerbates their feelings of helplessness and vulnerability. Some patients are proactive and ask to have the machine turned towards them, but many patients who aren't educated about dialysis wouldn't be able to understand the information on the screen even if they could see it. The dashboard makes the data both visible and accessible to patients by using an intuitive visualization to describe the system state during their treatment.

OWNERSHIP

By equipping patients with knowledge about their bodies and their treatment, it will help to reduce their fear and allow them to become active participants in their treatment. They can take more responsibility for their choices and their health, encouraging compliance with the treatment regimen that their doctor prescribes.

RELATIONSHIPS

The physical form of the armband metaphorically communicates to dialysis technicians that the patient is in charge of their body, and reinforces the patient's sense of autonomy. By empowering patients to take responsibility for their own health, it will make them feel less like they are being ordered around. By educating patients, it reduces the perceived power imbalance between patients and technicians, and hopefully facilitates positive interactions and learning opportunities.

TARGET USERS

The dashboard may be useful for a variety of patients, but will be most beneficial for both "passenger" and "driver" patients who have not found successful coping mechanisms.



TARGET USER #1: THE SILENT PASSENGER

Patients who have a "passenger" personality don't mind allowing the professionals to administer their treatment, but they may become depressed if they don't understand what's happening to them or have a voice in their treatment. These patients may not understand how dialysis works, adding to their feelings of helplessness and fear.



TARGET USER #2: THE BACKSEAT DRIVER

Patients who have a "driver" personality, but who are not able to do home dialysis treatments, may become especially distressed in a clinic setting. They are uncomfortable blindly trusting others to administer their treatment, and want to be able to observe and understand what is happening at all times.

06

REFLECTION & EVALUATION

The goal of this project was to understand how the design of medical devices can impact a patient's quality of life, and to explore ways to improve the patient experience through the design of the device itself. The dialysis dashboard successfully addresses that goal by allowing patients to regain a sense of control over their bodies and their lives.

PERSONAL REFLECTION

As a naive biomedical engineer, I remember the first time I heard of a patient voluntarily withdrawing from dialysis treatment. I was stunned - it had never occurred to me that someone wouldn't want to extend their life at all costs. It made me question my approach to medical device design. By just treating the medical issue it was solving the primary health problem, but creating a larger systemic crisis.

Throughout the course of this project, I met some wonderful people and heard touching stories. People who started off as just random strangers from the internet opened up to me about their lives, their struggles, and their fears. My Facebook feed has been dominated by posts from dialysis patients venting about their struggles, asking each other for help, or sharing their desperate hopes of getting a kidney transplant. I met people who had had kidney transplants that later failed, and I heard the nostalgia in their voices as they reminisced about how easy and carefree their lives had been. Above all, I was most overwhelmed by the reality that life is never going to significantly improve for these patients. They will never fully recover, and their only real hope is to make the best of their current situation. While dialysis technology has given them the chance to continue living at all, it also impacts the day-to-day interactions and struggles that these patients will experience for the rest of their lives.

For this reason, it is all the more important to be sensitive to quality of life issues when designing these devices. Seemingly insignificant design decisions can have far-reaching effects on a patient's overall experience, and could make the difference between having a life that is worth living versus one that is not.

DESIGN EVALUATION

Five key patients needs were identified during the generative research stage: health, time, mobility, purpose, and control. The dialysis dashboard mainly focuses on addressing the issue of control, but through secondary effects it addresses the some of the other needs as well.

Complex, life-sustaining medical devices such as dialysis machines may unintentionally contribute to a patient's feelings of being out of control of not only their body, but also their lives. For many people this can lead to depression, despite the fact that their physical medical condition is being successfully treated.

The wearable dashboard helps to alleviate some of these effects by giving a patients a sense of control over their bodies, their treatment sessions, and ultimately their overall health.

CONTROL OVER BODY

The dashboard externalizes the patient's current system state by using intuitive visualizations to make their information approachable and understandable. It communicates what is happening to their bodies during treatments to put the patient in control.

CONTROL OVER TREATMENT SESSION

By understanding what is happening to their bodies, it empowers the patient to take an active role in their treatment. It also helps to alleviate tensions between patients and technicians by giving patients the voice to effectively advocate for themselves.

CONTROL OVER LONG-TERM HEALTH

When patients understand how dialysis works and how their lifestyle decisions impact their health, it allows people to take responsibility for their treatment outcomes.

ALTERNATIVE FORM FACTORS

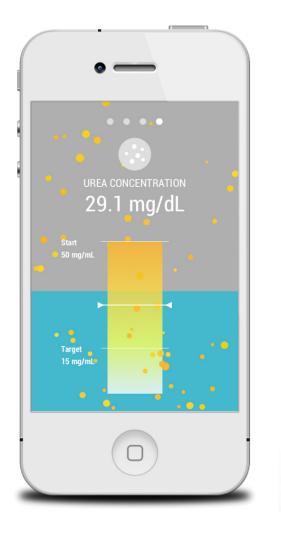
One of the main areas of feedback I received on my design solution was regarding the form factor. Some people thought it seemed too physically restrictive, unintentionally reinforcing the feeling of being shackled to the dialysis machine. Others thought it would be too unreasonably costly to create the device.

SMART PHONE OR TABLET APP

A more feasible near-term solution might be to use a smart phone or tablet-based app to display the dashboard instead. This would avoid the expense and logistical challenge of creating a new device specifically dedicated for this purpose. The drawback would be that it doesn't create as strong of a physical connection between the patient's body and the information displayed on the screen. Some people also thought that these platforms seemed too "informal" for displaying such serious medical information.

WATCH DESIGN

Another alternative design could be a dialysis watch. This is a much more familiar form that people are accustomed to wearing, as opposed to the armband. Although the screen size would be greatly reduced and it may not be as visible from an arm's length, the smaller size would be less physically restrictive. For patients who have fistulas (dialysis access points) lower down on their forearms, it would also help to avoid being in the way of any tubing.





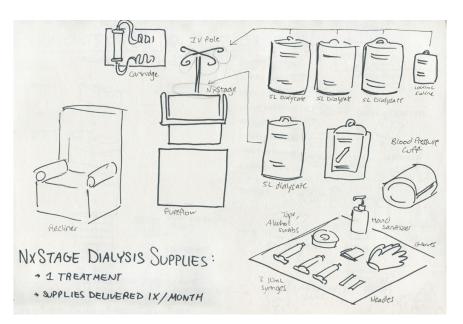
ALTERNATIVE DESIGN DIRECTIONS

One of the other design directions that I contemplated during this project, but did not end up pursuing, was a better solution for supply management in home dialysis.

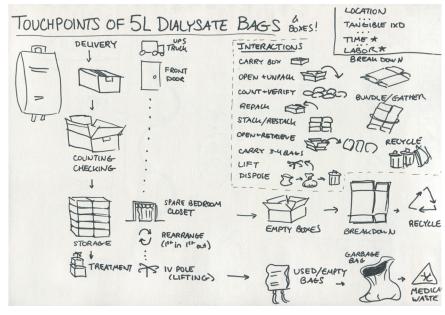
During my research, I was surprised that home dialysis users didn't find the usability of the machine to be an issue. Even though it takes six weeks of intensive one-on-one training to learn how to operate the device, they actually found this to be a positive experience. It was one of the few times that they had individual attention from a dialysis nurse, and learning this complex medical procedure (normally only performed by professionals) made them feel smart and empowered.

On the other hand, patients did not find any sort of satisfaction in managing the inventory of numerous supplies required to operate a home dialysis machine. Some patients reported receiving deliveries of twenty large boxes per week. The task of receiving deliveries, moving boxes, unpacking and organizing supplies, keeping inventory, breaking down and recycling empty boxes, and placing re-orders was a part-time job by itself. Furthermore, these tasks were purely drudgery, and did not provide the patient with any sense of pride or accomplishment. One woman remarked that she used to be a professional with a master's degree, and not only did dialysis take away her ability to work, but it also essentially made her into a low-level warehouse supply manager.

In exploring this design opportunity, I sketched out all of the supplies used in a single dialysis treatment, as well as all of the touchpoints for those supplies from the time they were delivered to the time they were disposed. Although I did not pursue this direction, a possible design solution could have involved a service to reduce the number of touchpoints that a patient had to deal with. Potential ideas included re-usable packaging to reduce the amount of disposable waste, or a standard supply organization system that would allow anyone (i.e. a helpful family member or a professional service) to help with the task of unpacking and organizing supplies.



SUPPLIES REQUIRED FOR A SINGLE HOME DIALYSIS TREATMENT



TOUCHPOINTS OF HOME DIALYSIS SUPPLIES

USER FEEDBACK

I distributed an online survey to dialysis patients via social media support groups in order to show them my design concept and gather their feedback. I received a total of 65 responses, which consisted of mostly positive reactions to the design, as well as some ideas for future improvement.

NEEDS MET BY THE DESIGN

Most patients agreed that they had faced the issue of feeling "out of control" at some point or another during their experiences of receiving dialysis. This need was mostly felt by those patients who received dialysis treatment in clinics; home dialysis uses said that doing treatments themselves allowed them to feel in control.

DATA VISUALIZATION

Users described the visualization as soothing, calming, comfortable, intuitive, and informative. The most common suggestions were to add blood pressure readings and to include a way to display (and explain) any alarms that occurred.

FORM FACTOR

The most common complaint about the design was the physical form. Patients were concerned about having to wear and be tethered to yet another device, and some people perceived it as something that would further restrict their movement.

ALTERNATIVE FORM FACTORS

At the end of the survey, I presented the two alternative designs (the phone app and watch concepts), and asked patients for their thoughts as well as which design they preferred. Although many people noted that the armband would be beneficial for people who don't have smart phones or for elderly people who aren't familiar with phone interfaces, the vast majority voted in favor of the app concept. Their main reason was that regardless of the cost of the device, they didn't want to wear something else since they already felt like they were losing autonomy over their bodies. 16 people preferred the armband, 44 people preferred an app, and 5 preferred the watch design.

I wouldn't want to wear [the armband]. During dialysis we're already tethered to the machine with needles. We have tape wrapped around our arm to hold needles and a BP cuff on our other arm. I don't want to have to wear anything else. Would love if this was an app on the phone or connected to our tv screen. 22

CONCLUSION

The overarching goal of this project was to recognize the role of medical devices in creating interaction and quality of life challenges for patients through the nature of their design.

Through my research, I found that the design of dialysis machines impacts a patient's experience on several different levels. Physically, the large size of the machine and the presence of needles and visible blood can initially be intimidating and can incite fear in patients. Functionally, the complexity of the device necessitates that the patient either travels to designated clinics to receive care from trained professionals, or they must undergo a lengthy training process to administer their own treatment at home. Emotionally and psychologically, factors such as the nature of the treatment, the service ecosystem that exists around the device, and the lifestyle restrictions that the treatment regimen imposes have a profound impact on a patient's quality of life. Overwhelmingly, all of these factors combined can make a patient feel out of control of not only their body, but also their life.

My design solution serves as an example for how negative effects such as these can be mitigated through the design of the device itself. Although further iteration on the design would be required in order to address all of the patients' needs, the approach demonstrates how devices can be designed to empower patients to feel in control during the treatment experience. This design approach would be applicable to a wide array of devices, beyond just dialysis. As heart pump and artificial lung technology advances to the point where more patients are living on these devices for extended periods of time, it will be equally important to address quality of life and patient autonomy issues for patients on those devices as well.

In conclusion, medical device designers and engineers should strive to develop empathy towards patients, and to understand the nonmedical struggles and quality of life issues they face, so that they can make decisions from a patient-centered perspective. Through this point of view, they will be better equipped to improve the overall treatment experience and quality of life for the patients they serve, in addition to improving their medical outcomes.

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