Patient-centered design concepts for cancer care interactions & experiences during chemotherapy

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Chemotherapy is one epicenter of cancer care that brings people and technology together in and around the infusion center. Within this space patients interact with providers and medical devices and these interactions shape their experience with chemotherapy.

This text explores how a patient-centered design process can address cancer care interactions with the aim of improving the patient's experience during chemotherapy. This process includes design-led research that is done in the field with patients, creative analysis that is informed by the perspectives of patients and conceptual design based outcomes.

The basis for this process was developed at the Seattle Cancer Care Alliance and the graduate design studio at the University of Washington.
MOTIVATIONS & BACKGROUND

One summer some years ago, at the age of 59, my father was diagnosed with stage four colon cancer. By the following winter, I had watched my father’s cancer wear down his large and sturdy frame to almost nothing. Earlier that fall my family and I had rallied around him as he endured several cycles of chemotherapy. Our hopes and, as my mother would later recall, “everything rode on the numbers”, or the results from countless blood tests that went hand-in-hand with the chemotherapy. Unfortunately, my father’s numbers left us with little hope and for the holidays he had opted to abandon the brutal drain of chemotherapy. By the end of that winter he was gone. In eight short months cancer had irreversibly touched my family and had given me a glimpse of the path that so many of us walk, or one day may walk.

The path of the cancer patient can be filled with suffering, frustration and uncertainty but it is also filled with people who are determined, hopeful and caring. Chemotherapy is one epicenter of cancer care where patients, providers and technologies converge all within and around the infusion center. The path of the patient through chemotherapy sees them interacting directly and indirectly with providers and technologies in this space and these interactions shape their experience. There is a quality attached to these interactions, a human dimension. Design work that attempts to address this dimension could be called patient-centered design.

WHAT IS PATIENT-CENTERED DESIGN?

The practice of healthcare inherently involves the patient, but institutions that practice healthcare must also consider themselves with efficiency and safety. A seasoned clinician and healthcare expert Donald Berwick has argued for a radical transfer of power and a broader meaning of ‘patient-centered care’. Dr. Berwick proposes that healthcare providers consider the human dimension at the same level they consider efficiency and safety. He defines patient-centered care as “the experience (to the extent the informed, individual patient desires) of transparency, individualization, recognition, respect, dignity, and choice in all matters, without exception, related to one’s person, circumstances, and relationships in health care.” While Dr. Berwick himself admits that his definition is “impractical”, it seems to resonate well with the attitudes of a changing society. Take for example the observations of IDEO’s Tim Brown, from his book Change by Design, he writes that “people’s expectations are evolving. Whether we find ourselves in the role of customer or client, patient or passenger, we are no longer content to be passive consumers at the far end of the industrial economy.”

Patient-centered design simply put, should serve the patient. It is primarily focused on improving the patient’s path through healthcare, or the interactions that shape their experience. It seeks to find ways to engage and involve patients in this space through interaction. Its practice should be informed by research performed by designers done in the field with patients.

“Patient-Centered Design Concepts For Cancer Care Interactions & Experiences During Chemotherapy”

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In 1998 Donald M. Berwick was part of a committee assembled by the Institute of Medicine (IOM) that focused on improving the quality of healthcare in America. The committee’s report, entitled To Err Is Human, documented the extent of patient harm that occurs in healthcare.
Such research enables designers to build, what Tim Brown describes as, "Bodies of insight through empathy, the effort to see the world through the eyes of others, understand the world through their experiences, and feel the world through their emotions." [2] It is important to note that patient-centered design is in no way diminutive or disagree the significant and critical work of experts in healthcare. Instead, it is dependent upon Bill Moggridge once wrote, "Designers rely on all the other disciplines, in that everything else has to work before design has a chance." [3] Working with healthcare experts and professionals designers can gain better access to patients, technologies, built environments and the professionals themselves.

Cancer patients are typically far from passive, making cancer care an ideal place for patient-centered design. Returning to chemotherapy as an example of cancer care, I wanted to explore how a patient-centered design process could improve the interactions and ultimately the experiences of patients during cancer care and chemotherapy.

METHODS

SUNRISE 2012

Initially I just wanted to meet with the people involved in cancer care, to dip my toe in the waters. Basically to develop an understanding of cancer care from the perspective of the patient. I have continued to meet with oncologists and nurses. I am a bit of an odd duck. Thankfully through a network of various contacts I have been invited to a senior researcher at a local healthcare research institute. This researcher then introduced me to a network of researchers at the Seattle Cancer Care Alliance (SCCA). Unbelievably there were willing to talk to me. After two months of looking, I was going to get a meeting.

SUMMER 2012

By this time the scope of my research interests were looking less like a dip and more like immersion. I wanted the chance to observe patients and healthcare providers during chemotherapy and document the interactions that occurred as a means to better understand the patient’s experience. Thankfully the meeting went well and getting the support of the SCCA proved to be critical to the rest of this work...
which significantly all of them did, then the interview would begin. To protect patient privacy I was required to obtain verbal consent from each subject prior to asking any question. I assured patients that the study was not obligatory and I explained the potential risks associated with participation, as minuscule as they might have been. Since the SCCA is a research center, most patients knew the drill better than I did and were comfortable with participation. I structured the interviews loosely, using the 20 questions as a catalog that I pulled from depending on how the conversation played out. I also tried to be cognizant of the patient’s mood and energy so as not to overwhelm them. The questions explored the patient’s experience with chemotherapy and covered topics that ranged from the patient’s daily routines to medical equipment to clinical care to support from family and friends (see 20 Questions at left). In the end I met with and formally interviewed 12 patients, one nurse and one oncologist. These interviews resulted in 507 minutes of audio recording and countless amounts of patient-centered information. Informally I interacted with and observed many nurses and patients and other things that occurred outside of my interviews. Often I found myself waiting for the next interview in the patient’s waiting area, watching patients come and go. I spent a good deal of time dodging nurses as they bustled about their duties. Ultimately just being present helped me to, as Jane Fulton Suri writes, “find a way to understand the perceptions, circumstances, habits, needs, and desires of the ultimate users.”

20 QUESTIONS

1. How many sessions do you anticipate of your cancer treatment? How long will it be, how often is it administered?
2. Walk us through the step-by-step details of a typical treatment day from the time you wake up until you go back to bed.
3. What equipment do you bring or do you use that equipment better?
4. What are you doing while you are waiting?
5. What equipment or device are used in your treatment?
6. How do you feel about them?
7. How would you change them?
8. Who interacts with or operates these devices?
9. What is physically the most difficult aspect of treatment?
10. During treatment what are your biggest concerns, worries or fears?
11. What are some of the questions you currently have or have had about your treatment?
12. What aspect of your treatment or progress would you like to be aware of or monitor?
13. Why?
14. What would you do with this information?
15. When receiving care what is most important to you?
16. Could you describe your interactions with nurses, doctors, etc.?
17. What things do you consider about treatment?
18. How would you describe your treatment environment with doctors and nurses during treatment?
19. How would you describe your interactions with doctors and nurses during treatment?
20. What about with your friends and family, the nonprofessional people supporting you?

Analysis

“Rarely will the everyday people who are consumers of our products, the customers for our services, the occupants of our buildings, or the users of our digital interfaces be able to tell us what to do. Their actual behaviors, however, can provide us with invaluable clues about their range of unmet needs.”

Evolving methods were used to make sense of the information, or the clues, that surfaced in the field interviews. Each method provided a frame for the information that helped give it meaning and made it more manageable. As this analysis evolved various patterns emerged as opportunities for design.
PATIENT-CENTRIC STORY GATHERING

This method was used to gather information generated during interviews. Which was stored, by hand, on a large piece of cardboard in the form of notes, sketches and diagrams. The information consisted of stories, quotes, ideas and inferences derived during and after the interviews. It was critical to capture this information while the experience was still fresh in the memory. Each piece of information was linked to the patient that was associated with it. This resulted in a patient-centric collection of the interview information. This was beneficial in that it created a base of reference for the information as a whole. It also established a single space where the information could be viewed collectively.
PATIENT-CARE PROCESS MODELING

An important part of understanding the patient's perspective is to learn about their passage through the clinic. This involves familiarizing oneself with the world of chemotherapy, the vocabulary, the procedures and processes that patients and providers use and experience throughout. To gain this understanding various diagrams and visualizations were used to model the systems, processes and flows that structure the patient's experience during chemotherapy. Modeling the information in this way helped in discerning the actualities of cancer care as well as in understanding the relationships that exist between patients, providers and their surroundings. Creating these abstractions provided a clear way to the discovery of design patterns and opportunities.

FAR LEFT: Model 1 - The basic steps of chemotherapy on a treatment day. Starting from when the patient steps into the hospital and ending when they leave. Includes critical procedures that happen away from the patient.

ABOVE: Model 2 - A linear view of a chemotherapy day. Includes patient's day away from the hospital.

LEFT: Model 3 - This model builds on models 1 and 2. It factors in time, with each circle representing typical durations of time for each step within the hospital.

LOWER LEFT: Model 4 - The path of the patient.

LOWER RIGHT: Model 5 - This model looks at point of interaction between people and technology within the infusion center.
In order to make more sense of the interview information it needed to be framed in a way that separated it from the patient and ordered it by information alone. To do this I transferred key stories and information from the patient-centric story gathering method onto unique post-it notes. This made the information sortable, in that each piece of information was isolated and mobile. The information was then clustered around commonalities that were based on initial insights. This process helped to establish emergent themes.
Framing the information into clusters allowed for a new analysis of the information as a whole. The individual pieces of information were reshuffled, understood, and related in new ways. Exploring these new relationships enabled the discovery of new patterns. Eventually, these patterns formed into themes, which provided the foundations for the development of design ideas.
IDENTIFYING AREAS FOR DESIGN INTERVENTIONS

Looking at the information through the lens of themes made the information more insightful and helped to identify the opportunities that appeared most promising. These opportunities initiated the exploration of design interventions and creative problem solving that resulted in five design seeds.

UPPER LEFT: The method started with blank sheets of paper that represented each area.
LOWER LEFT: By the end of this method the areas had been narrowed down and filled with design ideas.

RIGHT: Design ideas were explored through notes, sketches and pictures.
“That insight cannot yet be codified, quantified, or even defined—yet at any rate—makes it the most difficult but also the most exciting part of the design process. There is no algorithm that can tell us where it will come from and when it will hit.”

These five design seeds represent the design-based outcomes of the research and analysis. Each seed conceptualized is rooted in the information gathered during research activities. The problem and definition of each concept stems from the discoveries generated in analysis. These seeds are not refined designs but are more like refined opportunities for design.
In interviews patients talked about owning their cancer, taking control of their treatment and saying no to procedures. They also talked about finding the right doctor, someone who was on their team. Patients felt encouraged that their cancer teams had meetings about them—even when they weren’t there. Patients valued doctors who talked to them like they were equals or like they were working together.

Co-Care: Improving chemotherapy experiences through patient involvement and collaboration.

History:
Chemotherapy typically requires a team of medical professionals. From oncologists to nurses to nutritionists and physical therapists. Finding the right team can make a big difference in a patient’s treatment and their overall experience. The quality of communication between the patient and their team is equally important. The relationship between the patient and their team can be shaped by a sense that the team is on their side, working together on their behalf. Traditional delivery of care is solely handled by providers, but benefits can be gained by getting the patient involved in their own care.

Problem Statement:
What if there was a tool that helped patients get involved in their own care and encouraged a team-like relationship with their cancer care providers?

Problem Description:
This tool could build beneficial relationships between patients and providers through involvement, transparency and collaboration during chemotherapy and cancer care. It could be useful to both patients and providers. It could also provide a trustworthy means of communication that connects providers and patients alike.

Constraints:
The tool cannot hinder the delivery of care in any way or create additional burdens for providers. Instead it should create a superior working system that helps providers do their jobs and connect to the people they serve. The tool cannot endanger the safety or privacy of the patient in any way.
Research helped reveal the relationships that patients form with the medical equipment they end up spending a lot of time with. Some of these relationships were positive and some of them were negative. For example, some patients hated the beeps that infusion pumps would make, while others were assured by a steady, quiet pumping sound and others found equipment awkward or endearing.

**DESIGN BRIEF**

_alternating interactions: inviting patient-device interactions and relationships._

**History:** Chemotherapy patients spend a great deal of time surrounded by equipment that is critical to their treatment. While they are exposed to this equipment, they naturally develop relationships with the equipment. These relationships can be based on anything from annoyance to admiration. At the same time, interaction with this equipment is typically one-directional from the patient’s perspective.

**Problem Statement:** In what ways could patients interact with medical devices that are based on existing or newly imagined relationships?

**Problem Description:** These ways could invite patients to interact with devices that they don’t typically interact with. Each interaction and relationship could inform the patient’s experience and help make that experience positive.

**Constraints:** These interactions and relationships cannot interfere in any way with treatment, or the critical functions of medical equipment. Providers should maintain exclusive control and access to provider-level functions of medical equipment.
Patients often experience anticipatory nausea, which can be alleviated through distraction. Patients find themselves wishing that they could be active while dealing with the inevitable waiting time that occurs with chemotherapy. Also, patients and providers deal with an incredible amount of available information, both good and bad.

**Problem Statement:**
What if there was a game that could be played during chemotherapy that allowed for interactions between patients and providers?

**Problem Description:**
The game could facilitate the distribution of useful information from providers while making it fun for patients to learn. It could also provide distraction for patients. The game could be played while patients are receiving their infusions, but it could also be played in other waiting areas experienced by the patient.

**Constraints:**
While competition can help to make the game more interesting and fun, it should be handled in a way that avoids conflict and protects the patient's privacy and safety.

**DESIGN BRIEF**
In-chemo Play: Patient gaming as a form of distraction and education.

**GAME**

**PROVIDER**

**PATIENT**

**NURSES**

**DOCTORS**

**SPECIALISTS**

**PATIENT**

**TRIVIA**

**DESIGN SEEDS**
Design Seeds | 2625

| Patient-Centered Design Concepts For Cancer Care Interactions & Experiences During Chemotherapy

**LEFT**
What if a game enabled interaction between patients and providers.

**RIGHT**
In-Chemo play concepts.
Patients usually spoke about being nervous and afraid before their first chemotherapy experience. Most patients felt like they overcame this by learning the routine and becoming familiar with the experience.

**CHEMO CO-OP**

**Design Brief**

**Chemo Co-op: Overcoming anxiety with an experiential learning process.**

**History:**

**Problem Statement:**

This design could create a system that helps patients, working closely with their nurses, be a part of shaping their first and subsequent chemotherapy experiences.

**Problem Description:**

This design should create a system that enables patients and providers to proactively shape the chemotherapy experience. This can be accomplished by engaging the patient in the process before they are exposed to it. This can also help patients develop a good working relationship with their providers prior to their experiences with chemotherapy.

**Constraints:**

Pluses and minuses in efficiency and patient experience should be taken into consideration and weighed against each other. Added workload for infusion nurses must also be considered, and potentially represent an opportunity for the patient.
Chemotherapy is a complex experience filled with physical and emotional challenges. Typically this occurs within a single space, a bed, a chair or a room. Patients often develop anxious associations with their surroundings. Some patients talked about communication challenges between themselves and providers. Additionally, it is in this space that patients spend hours waiting to get “unplugged” so they can get back to their lives.

**DESIGN BRIEF**

**Responsive Rooms: Transforming experiences through responsive environments.**

**Problem Statement:**
What if the patient’s environment responded to their behavior or needs?

**Problem Description:**
These responses or adaptations could create a better experience. What inputs the room responds to might be as important as the responses themselves. These responses could be incorporated into existing objects, or they could be new features.

**Constraints:**
The design should make the room serve the patient as well as providers who must do their work within this space too.

How might rooms respond to patients to better serve them?

**DEVICE**

**SUPPORT**

**PROVIDER**

**PARENT**

**SLEEPING MODE**

**DYNAMIC SURFACES**

**MOOD/STATUS INDICATORS**

**MESSAGING**

**RESPONSIVE ROOMS**
REFLECTION

This project was an eye-opener for me and through it I learned a good deal about working with people, field research and empathic design. In the beginning I was not experienced and new at the skill. I tried to do my own exploration and thought from the research and people I interviewed. I could have saved a lot of time by seeking help from experts, but I do have some ideas on how design work might be done in healthcare.

Time was my biggest enemy. More time I could have employed a wider variety of research methods that might have led to additional insights and opportunities. These methods could come from the IDEO’s Method Cards or from the Royal College of Art’s website designingpeople.org or a completely new method developed specifically for cancer patients. Using such methods would require more planning and probably a longer more difficult IRB approval process.

Working alone has its limits. Doing this work as one designer was mostly unavoidable, as this was part of a master thesis project. This is not to say that I did not have help or that the partnerships that I developed were not essential. I do believe that working alone has its limits, when in fact they were essential. I do believe that using a team of mixed professionals would be better suited for the task that I pursued alone.

There is still much to be done and a lot of opportunity on the table. The design needs generated by this project are only the beginnings of hopefully much more patient-centered design work in healthcare. I believe that any future patient-centered design work would benefit from the development of an iterative prototyping model that keeps the patient at the center, as Bill Moggridge once said, “I believe that if we think about design and try again to prototype our design, we stand a good chance of creating innovative solutions that will provide value and joy.”

SUMMARY

The development of more advanced treatment technologies, in certainly a good thing for cancer patients, but it is not the only thing. In an article published in Health Affairs in 2009, Donald Berwick noted that, “Medical education experts say the human dimension is sometimes crowded out by discussions of the latest technological innovations.” Such a focus on technology certainly leaves the patient’s experience lacking. Or as Tim Brown puts it, “technology alone does not necessarily result in a better customer experience.” Patient-centered design that puts designers in the field, has them doing research directly with patients and connects that research to design and concept development is well suited to develop these improvements.

Chemotherapy is just one of potentially many paths that patients walk. My father’s cancer was an intimate connection between me and this path. At the beginning of this project I thought that I had a pretty good understanding of that experience, having had someone close to me go through it. After talking to people, observing them and being present on that path I have realized that I still have a lot to learn. I hope to continue in the search of insight and the development of good things that will help people who walk the path my father walked, the path of the patient.

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