Cancer Treatment Side Effect Management (CTSEM)
CSE 440 AB
6 February 2017

2h: Final Report

Title

Our group project name is “CC:”. This is meant to be intentionally ambiguous because it could refer to the email protocol “Carbon Copy” since we are forwarding information to the caretakers, but it could also refer to “Collaborative Care”, or more plainly “Cancer Care”.

Each Team Member’s Name and Role(s)

- Alison Maher: CEO, external relations manager, interviewer
- Clara Lu: COO, product manager, team cheer leader
- Peter Li: CDO, creative designer, writer, and comic artist
- Sam Crow: CTO, editor and comic artist

Problem and Solution Overview:

One of the main problems with cancer treatment is that patients have to keep track of various pieces of information, including side effects, medications, appointments and bills. Caregivers rely heavily on the patient’s memory to help explore solutions for their symptoms, and remembering these details week to week can be challenging for both parties. Our proposed solution at the beginning of this project was to streamline the tracking process for patients and provide simple means of communicating this information to caregivers.

Design Research Goals, Stakeholders, and Participants:

The main goal of this project is to help caretakers and cancer patients track symptoms and solutions that work across populations. The project will support documentation of alternative solutions to side effects that are rarely formally recorded by the caretakers or shared across time spans. The stakeholders that are involved include cancer patients, family members, and caregivers such as doctors and nurses.

In order to evaluate the needs of our stakeholders, we interviewed a current oncology nurse at Swedish Hospital. We also interviewed a researcher/cancer survivor as well as a family member of a cancer patient. We tried to reach out to medical students and a former mentor at the Seattle Cancer Care Alliance who is a research nurse. Ideally, we would have also contacted current patients through these connections. However, HIPAA regulations and time constraints prevented us from accessing patients.

We initially conducted a forum study and analyzed previous research, which allowed us to quickly gain a broader understanding of the needs of different stakeholders. Next, we conducted one-on-one interviews with stakeholders. This method made the most sense in the context of our project due to HIPPA regulations. We didn't have sufficient time to receive clearance to conduct a contextual inquiry given the time constraint of this project. We crafted interview questions specific to each stakeholder before each interview.

Design Research Results and Themes:

Throughout our various interviews, we discovered some common themes. There are many different groups of stakeholders, but they all have very similar needs.

First, we noticed that most patients track symptoms solely by memory. This poses a major problem considering that many patients struggle with their memory due to medications. They also struggle to communicate their symptom history due to fatigue and the amount of information they have to track. This suggests that a self tracking tool would be valuable, however it must be easy to use. If at least some of the tracking were automatic, it would ease the burden of logging the requisite information, which is a common reason people burn out of self tracking. Finally, having a calendar would also be helpful because it creates a structured schedule that the patient should follow.

We also noticed that current tracking techniques do not provide an analytical history of symptoms. This information could help people understand the trends of symptoms and manage them. Providing a platform to connect patients with others who are undergoing similar side effects was another common finding. Improving communication between healthcare providers and patients proved to be another area of focus. A way to visualize and export previous data, such as what days one had certain symptoms would be helpful, especially for caretakers.

Another theme that was evident across all stakeholders was the need for a concentration of related information. Before being diagnosed, most patients do not know about common side effects of treatment, other than perhaps hair loss. It would be useful to include information and training about side effects such as immune system suppression and neuropathy. If we included details about potentially extreme side effects as well, this would allow the patient to know whether what they are experiencing is normal. This information would benefit both family members and patients.

Among family, survivors, and forums, we also noticed a need to share personal information in some way. Some type of in-app messaging system would let people reassure one another, as well as ask each other relevant questions about their treatments. It is easier to connect with people who are going through similar experiences, and thus a platform specific system would be more beneficial than a standard social media platform.

Answers to Task Analysis Questions:

1. Who is going to use the design?

Cancer patients, caretakers, cancer survivors, family members, and health care providers will use the design.

2. What tasks do they now perform?

- Cancer patients track various pieces of information, including symptoms, medications, bills, appointments, etc. Most often this is tracked mentally.
- Caretakers track symptoms via verbal communication with patients and using online flowcharts.
- Family members assist patients with tracking in order to better care for them.
- Cancer survivors often volunteer to assist current patients in their local area.

3. What tasks are desired?

- Viewing an analytical history of symptoms to better understand trends of conditions and better treat the symptoms.
- Ability to share self tracked data with caregivers and providers.
- Connect patients to other patients and survivors.
- Make self tracking easier - automation, notification and possibly through voice command.
- Having one place to keep all information regarding treatment (ex. appointments and medications.)

- Provide a preselected set of symptoms to track based on type of cancer and treatment.
- Provide a way to customize the symptoms they are tracking.

4. How are the tasks learned?

- Most of the tasks are learned from nurses and other care providers, as well as through connections with other patients they meet in the waiting room.
- Many patients also use online resources to learn these tasks, but most are learned through trial and error.
- Nurses learn tasks through education, training, and exchanging ideas among colleagues.

5. Where are the tasks performed?

Tasks are performed in clinics, hospitals, home environments, and during everyday tasks (ie. anywhere the patient experiences side effects of treatment.)

6. What is the relationship between the person and data?

The data is usually collected using the memory of the patient or through some other tracking system, such as a notebook or journal. Nurses usually access the data through conversation and record it in the online flowchart. Family members interact with the data through conversation or by directly observing side effects.

7. What other tools does the person have?

All of our stakeholders have access to the internet. As mentioned in our interviews, many patients have access to some sort of smartphone or tablet during treatment, and most use the internet to research solutions to various side effects. The nurse we interviewed uses an online flowchart tool to assist in the tracking of symptoms. Other sources of information come from physicians and other health care providers, and from other patients and survivors who may be willing to share ideas with one another.

8. How do people communicate with each other?

Cancer patients communicate with nurses and other caregivers about their symptoms and learn about the details of their treatment through face-to-face conversations when they are at the clinic or hospital. The provider can then access that information collected by nurses in an online flowchart, where the information about side-effects is often segregated into different sections. Patients may talk with one another in the waiting room, where they exchange experiences about their own treatment and tips on how to better manage side-effects. Patients sometimes can get introduced to a cancer survivor or mentor through their clinic or community to gain information about what to expect.

9. <u>How often are the tasks performed?</u>

Patients may track their symptoms as often as every few hours depending on the frequency of symptoms. Patients communicate with caregivers about their side effects during every visit to the clinic or hospital, which can vary from weekly to monthly. Patients meet each other and exchange information when they are in the waiting room for their various appointments.

10. <u>What are the time constraints on the tasks?</u>

Managing side effects of treatment can be a time sensitive task. Many times, knowing when side effects occur is helpful in knowing how to better treat the symptoms in the future. For example, knowing when one experiences nausea helps patients better plan for when they should take anti-nausea medications in the future. Thus, tracking symptoms is time sensitive in that the tracking is most effective when conducted in real time. Also, knowing when to take medications and when one's next appointment is can be extremely time sensitive. If patients don't keep track of when these time sensitive tasks must be completed, they may experience road blocks in treatment. Thus, keeping track of the time of specific events can be extremely beneficial towards tracking and managing treatment side effects.

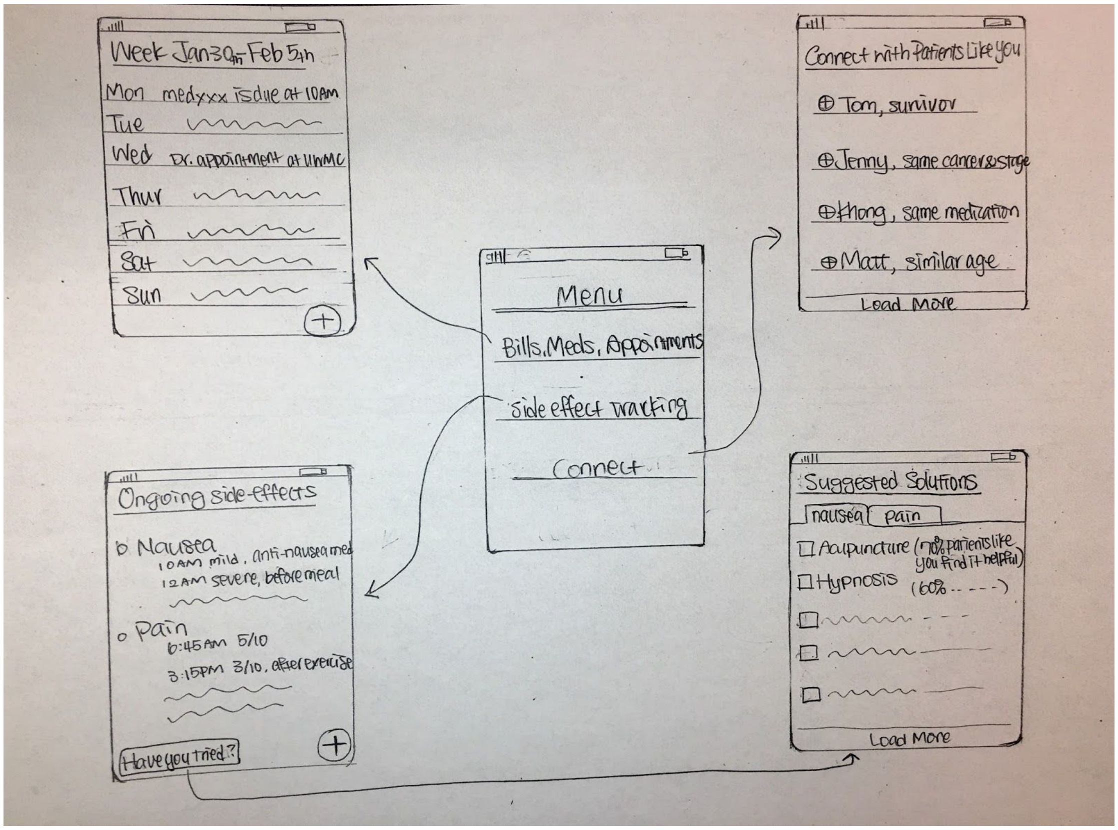
11. <u>What happens when things go wrong?</u>

If patients or caretakers do not accurately track symptoms and methods used to manage them, finding solutions may become difficult, and patients can suffer from more severe symptoms. When patients forget to take medication, they temporarily lose the benefits that the medications provide and may experience more severe forms of the conditions being treated. If a patient fails to record a symptom management technique that does not actually have any effect, they may waste time later unsuccessfully using that technique.

Proposed Design Sketches - "3x4":

<u>Design 1</u>: Patient Focused

An app where patients can manually track their side effects and other information. This would be a useful design if patients want to choose what data they share with others or if we cannot fully integrate with caregivers and providers. Because the entire user base would be made up of patients, we figure it would be simple to connect them to one another based on type of cancer and type of treatment.



- Task 1: Keeping track of bills, medications, and appointments
  The application displays tasks and appointments in a calendar-like view. Users can navigate through the calendar to view various points in time. They can add tasks and appointments by entering their times and other information. The application reminds users about tasks and alerts them in advance of appointments.

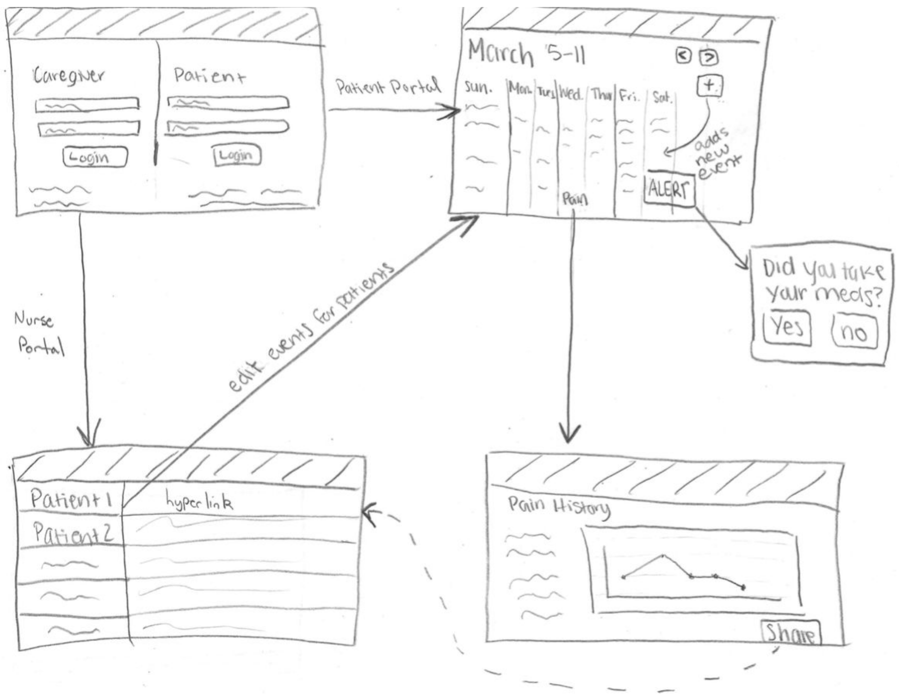
- Task 2: Tracking side effects after treatment
  Users can record the side effects they have experienced. Each side effect appears in a list. For each side effect, users can enter notes about how they have experienced that side effect

and record its severity over time and whether each of the solutions they have tried work or not.

- Task 3: Connect with similar patients and survivors
  Based on information the user has entered about their cancer type and demographics, the application suggests other users that they might like to communicate with. Once two users agree to connect, they can share information and communicate through written messages.
- Task 4: Explore solutions to side effects
  After users enter the side effects they have experienced, the application can display possible management techniques for known side effects. It incorporates suggestions from other users and reports about the effectiveness of the techniques.

Design 2: Patient-Caregiver Interaction Focused

Our design is a web portal with two separate interfaces, one for patients, and one for caregivers and providers. This would improve communication between the two stakeholders and eliminate the extra effort for patients when recapping their status. Some sort of graphical view would benefit both parties in analyzing trends and previous reoccurances of certain side effects. This design would support the ability for caregivers to input additional information such as appointment dates and medication doses/schedule.



- Task 1: Keeping track of bills, medications, and appointments, and Task 2: Tracking side effects after treatment

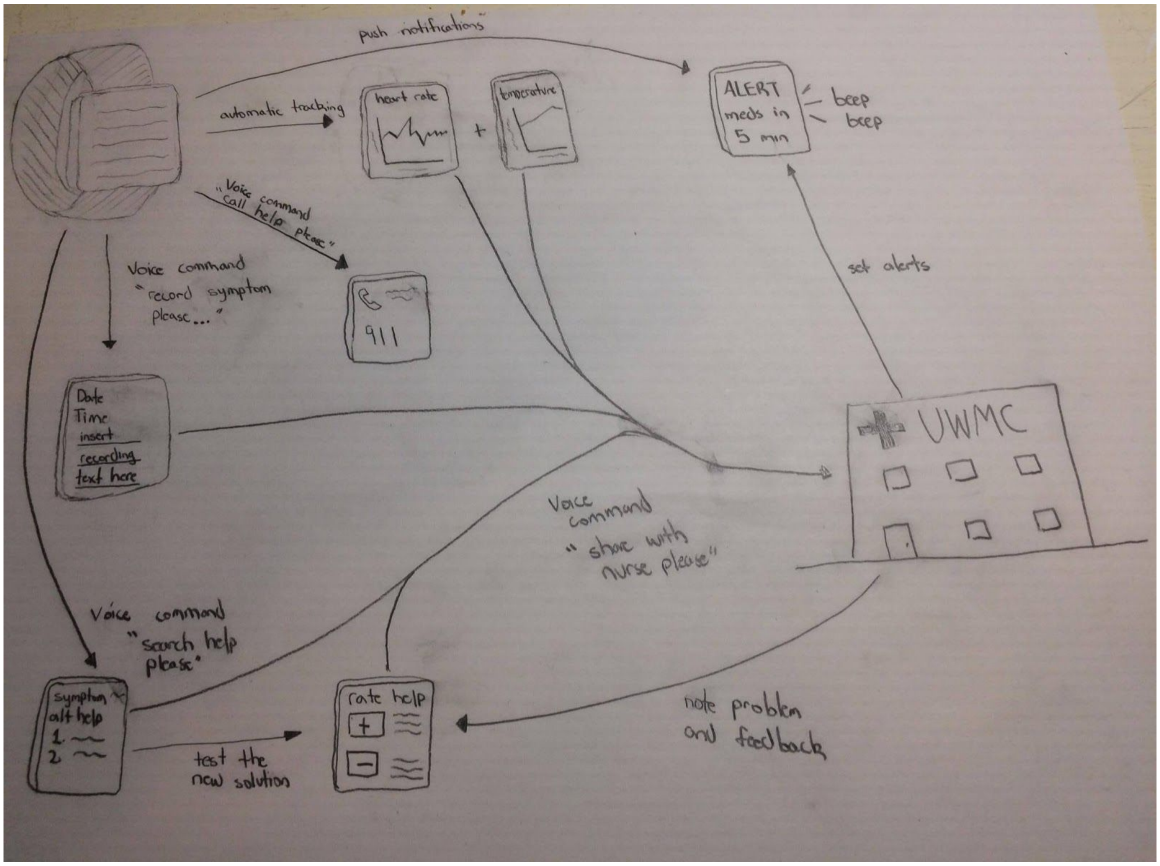
  Patients can track symptoms and other information such as bills, medications and appointments in the calendar view. To create a new event or symptom, the patient or nurse can click the "+" at the right hand side of the page. If side effects are tracked in the calendar, patients can open a link to the analytical view for that symptom. If it is time for a specific event, the calendar will notify the patient.
- Task 3 Combining the results to view an analytical history of the data

  Given the information that the patient has logged on the calendar, then can click certain attributes to see the history of that symptom. The graph displays other relevant data to the event that was added on the side.
- Task 4: Share progress with caregivers and providers

  Caregivers have the ability to edit items (solutions to certain symptom, medications, upcoming appointments, treatment options, and ect.) in the calendar. If patients choose to share their side-effect tracking history with the caregivers, caregivers will also have the access to the analytical view of the history.

<u>Design 3</u>: Automatic Tracking/Voice Tracking + wearable device (watch)

A wearable device that would automatically track side effects through voice command. This can be a helpful design especially for patients experiencing fatigue and memory weakness given the ease of use. The device could easily track and remind patients of important events, such as when to take their medications. This could also potentially be tracked wherever is convenient for the patient.



- Task 1: Keeping track of bills, medications, and appointments, phone numbers
  Caregivers can upload data to the device, such as when the patient's next appointments are, when the patient first took their medication/how often they should take it, important phone numbers, etc. The device will automatically notify the patient to remind them of these events using a sounded push notification.
- Task 2: Tracking side effects after treatment
  The device tracks side effects through voice command, easing the tracking process and reducing fatigue. The device will automatically note the date and time when side effects are tracked. Both quantitative and qualitative data will be recorded.

- Task 3: Share progress with caregivers and providers
  Patients can directly share the data they collect with their caregiver through simple voice commands. The data surrounding the side effects, the data collected through automatic tracking, such as heart rate and temperature, and the data collected about the success/failures of various solutions can all be shared with the patient's caregivers.
- Task 4: Explore solutions to side effects
  Patients can explore solutions to their side effects through voice command. The device will suggest various solutions to try. The patient can then rate these solutions - whether or not the solutions worked for them. Caregivers can also add feedback and note any suggestions through an integration with the device.

In the end, we realized that we liked certain elements from each of the designs. We liked the automatic tracking a wristband/smartwatch could provide, the mobile app is needed in order to provide functionality that the wearable could not provide such as data visualization or a calendar view, and the nurse portal is needed in order to share the patient's information for improved treatment. We ended up combining these three aspects into a more concise design. The tasks we wanted to focus on were the actual tracking of symptoms, without which our design would be useless, and the social connection with other patients, which is a unique characteristic of our design that other current apps don't have. We want the wearable to be as simple as possible, potentially containing only a speaker to relay results, a microphone to record inputs, and a few basic biometric sensors to automatically track information. This syncs over bluetooth with the phone, where the patient can then choose when and what to push to the caretaker. Our design focuses on making treatment easier for the patient, and allows them to control what data to share, in case there might be any information they consider to be sensitive.

Written Scenarios - "1x2":

Storyboard 1:

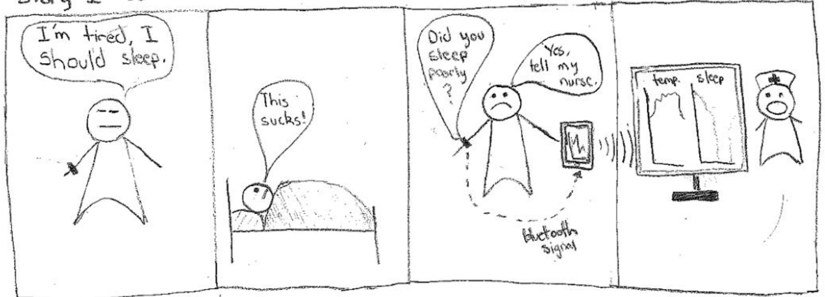
During Alex's chemotherapy treatment, he developed a fever due to his low white blood cell count. He experiences wild temperature fluctuations which have caused him to become very uncomfortable. His wearable has been tracking his sleep habits, and notices him being very restless when he is trying to sleep. Based on the data is has collected, it decides to check up on him. Alex wants to contact his caregiver, so the device pairs with the phone and sends the graphs of the data to the nurse. The nurse tells Alex to take some anti-inflammatory drugs, which help him regulate his temperature, and allow him to sleep normally. Now Alex is more comfortable and in a better mood!

Storyboard 2:

George has been undergoing chemotherapy treatment for his thyroid cancer. Over time, he noticed that there were sores developing in his mouth, and no matter what he tried he couldn't stop the pain. They started preventing him from falling asleep, so he opened up his CC: app on his phone. He searched first for people with his type of cancer to no avail, and then searched for people with the same side effects. The app suggests Olivia, a current leukemia patient, as a match. As the two chat about the side effects of their treatment, she suggests magic mouthwash as a way to combat his mouth sores. George had never heard of this treatment, but asked his doctor for some, and now he is able to sleep properly. He thanks Olivia for her suggestion and time. They remain friends to this day!

Storyboards of the Selected Design

Story 1 round 2:

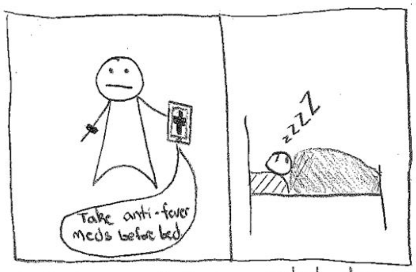


patient with wearable tracker

a few hours later

in the morning, wristband notices something was off

wristband data sent to nurse who sees a trend



nurse gives feedback

patient sleeps soundly

Story 2