



# PEER UP for Cancer

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Thesis Process Book 2017

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## INTRODUCTION




Usually 25% to 30% patients with cancer receive chemotherapy as a treatment option and 70% to 80% of these patients undergoing chemotherapy exhibit nausea and vomiting as major symptoms.<sup>1</sup> After receiving chemotherapy, patients would have

side effects like feeling extremely tired, pain, nausea and sometimes it's hard for them to get up by themselves to the bathroom. Patients need help with some daily life activities. But the time when they need help most, is also the hardest time to ask for help.

On the other side, when friends find out the patient has cancer, they would like to help and support but don't know what to do. And friends also would consider whether their relationship is close enough to offer help and let the patient feels comfortable with it.

# PROBLEM STATEMENT



Young adult cancer patients who are in early stage of treatment process often have difficulties communicating about what they need with people who could offer help.

# OBJECTIVE



The objective of my thesis was to provide a tool to facilitate the communication between patients and their friends to let patients feel more emotionally and socially connected with their support network, and their needs get met more easily with less distress, which could improve their physical and mental health outcomes.

# TARGET AUDIENCE



**Young adult cancer patients living in the United States who are 20-35 years old.**

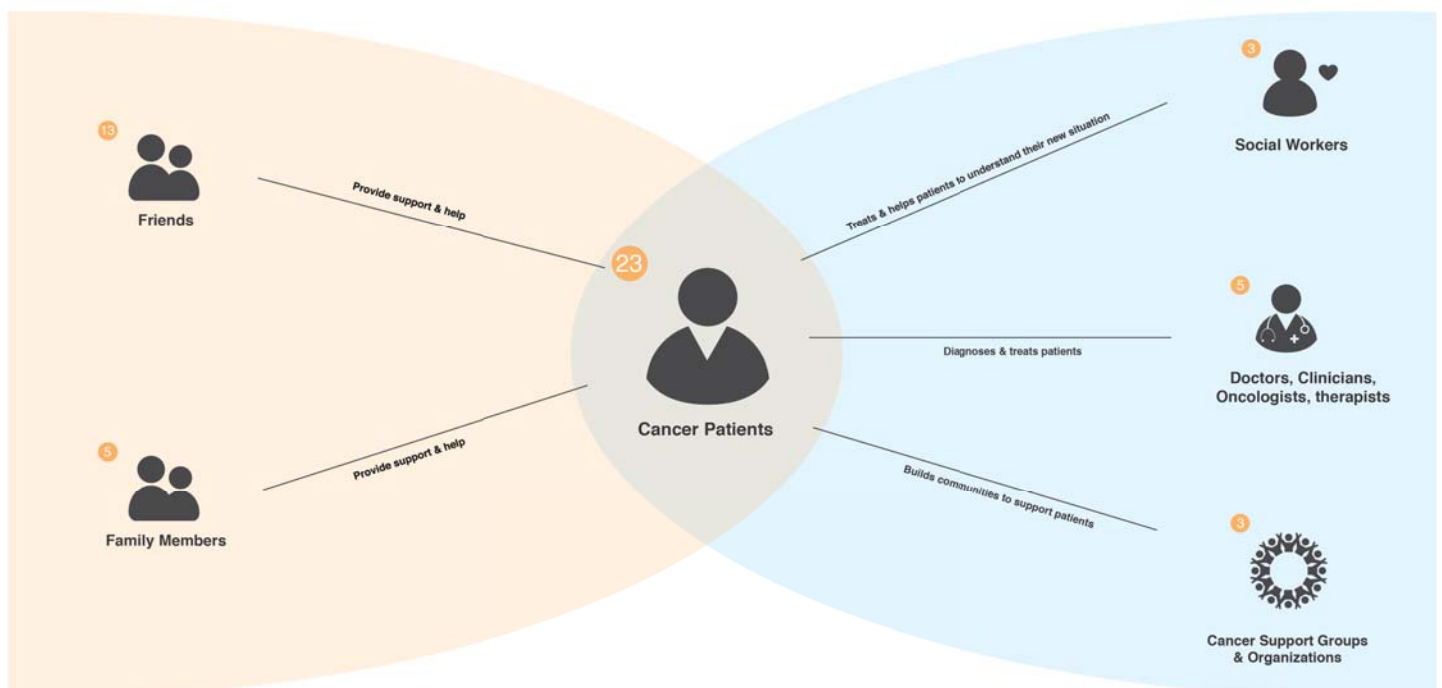
People in this age range, they have larger social network in daily life, have more different kinds of connection with people, want to show independence in front of others. "Some of the greatest challenges faced by young adults with cancer come from the fact that this tends to be a time of great change in a person's life, which comes with many of its own stresses. Young adults are often establishing their own identity

at this time and developing their own social, emotional, and financial independence. A diagnosis of cancer can throw all of these things into disarray."<sup>2</sup>

Every year more than 60,000 young adults aged 20-39 are diagnosed with cancer in the United States. About 4% of all cancers are diagnosed in people in this age range.

# STAKEHOLDER MAP

In order to understand the situation that patients are facing, I immersed myself in the environment. I have interviewed 23 patients, 13 of them are young adult cancer patients. 13 patient's friends, and other stakeholders.





# CURRENT REALITY



In this stage when patients need help, they would ask for help from average about 5 people: their parents, husband or wife, relatives, and friends who they have many years friendship with. But the small support system may not offer the help to patients all the time, especially for people who live long distance away from their family. On the other side, when friends find out the patient has cancer, they would like to help and support but don't know what to do. And friends also would consider whether their relationship is close

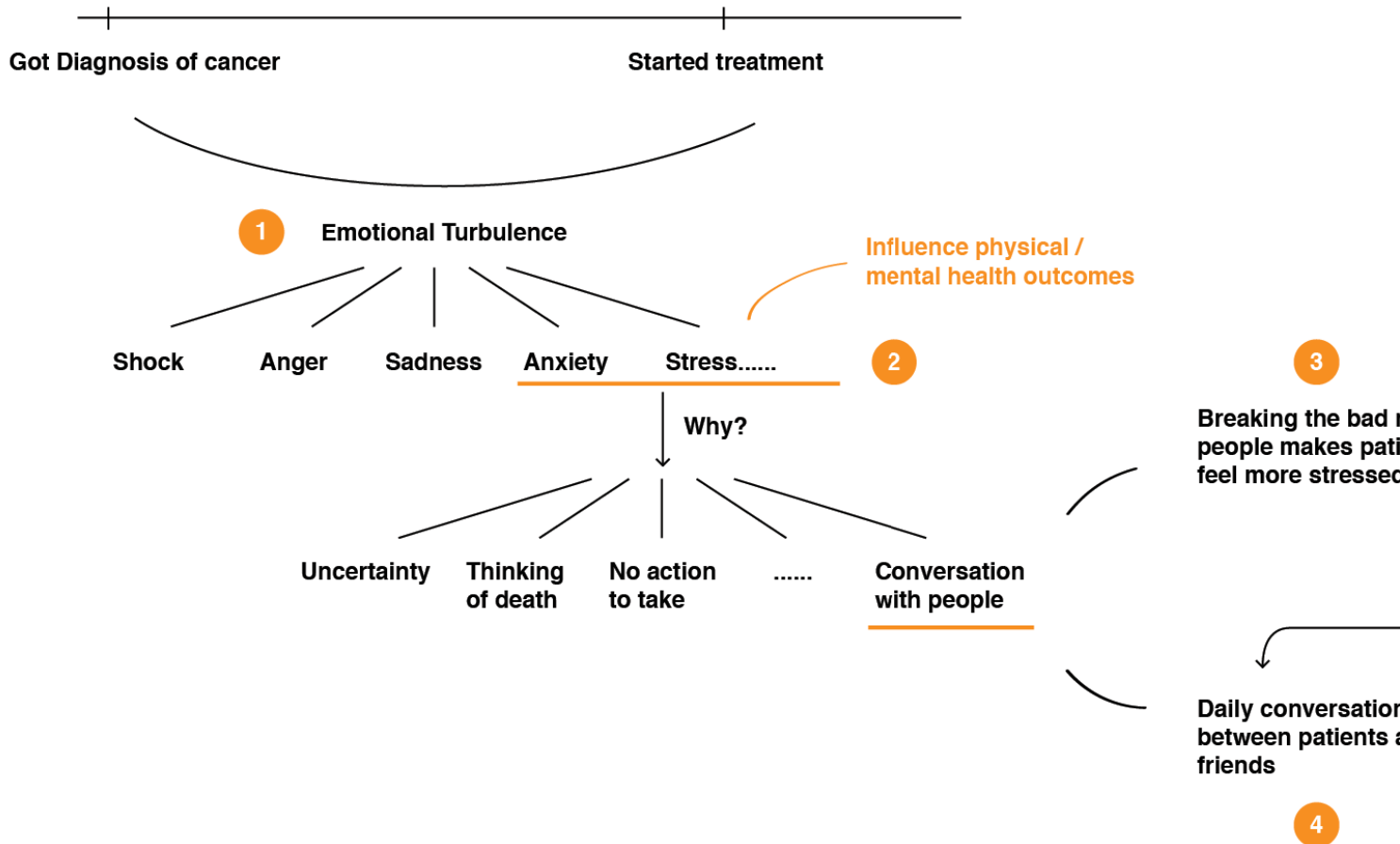
enough to offer help and let the patient feels comfortable with it.

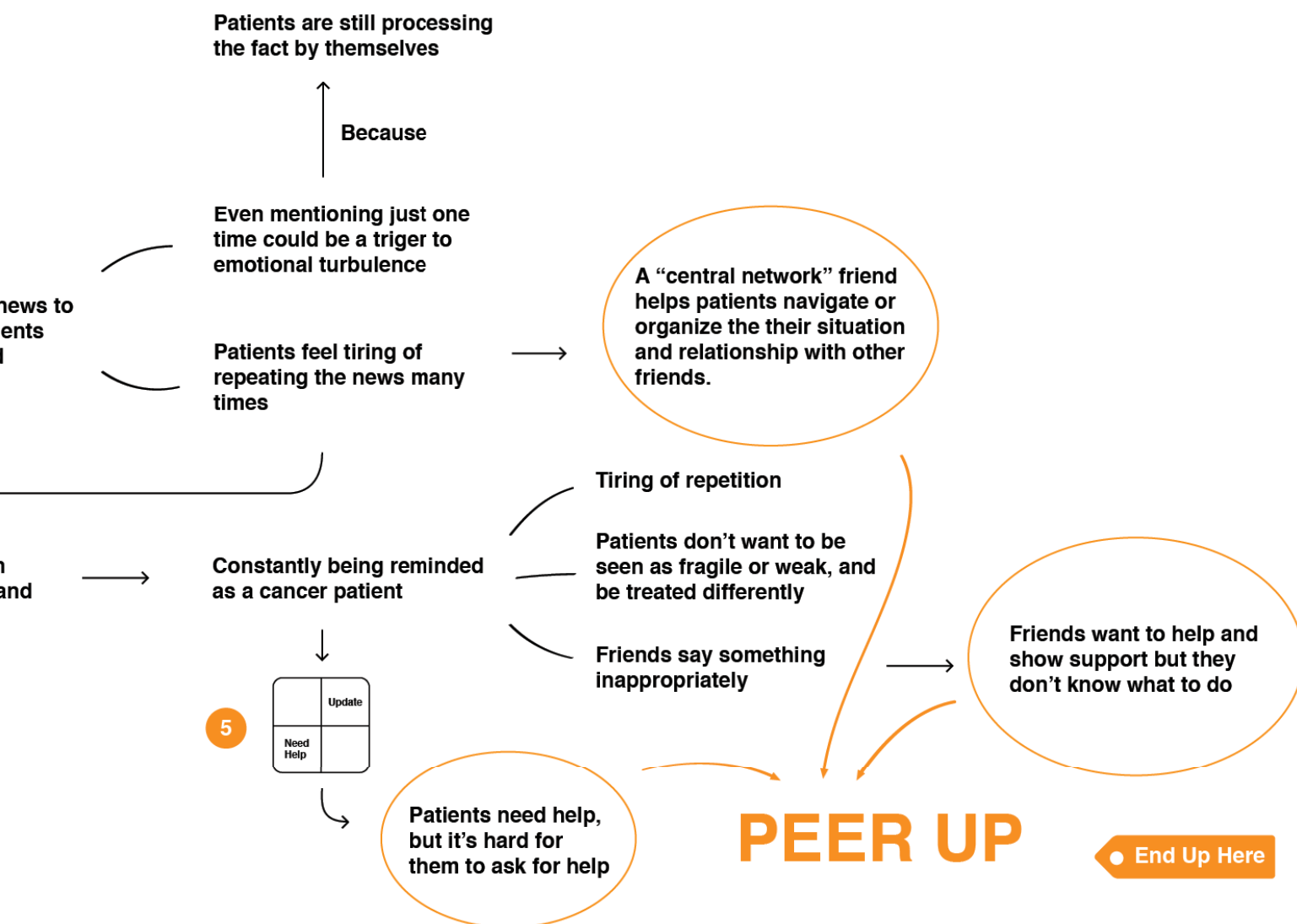
Cancer and its treatment can weaken patient's immune system by affecting the blood cells that protect us against disease and germs. As a result, patient's body can't fight infection, foreign substances, and disease as well as a healthy person's body can.<sup>3</sup>

So patients have to spend a lot of time stay at home which makes them feel disconnected with their friends.

# PROCESS


Start Here •





1

# EMOTIONAL TURBULENCE



## Question for myself:

What emotions do patients have when they initially got diagnosis of cancer?

## Research:

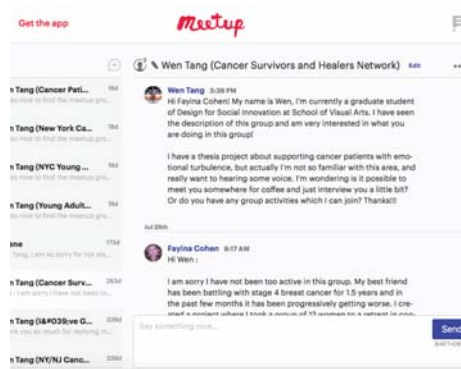
- Second hand research
- Interviewed patients, family members, doctors, people working in organizations, social workers

## Learnings:

- In the diagnosis stage, the pain point for cancer patients is they would feel shock and crisis, feeling betrayed by their body, fears of incapacitation and death, and how do they tell people.
- People feel stressed to be positive.
- Stress can be caused both by daily responsibilities and routine events, as well as by more unusual events, such

as a trauma or illness in oneself or a close family member. When people feel that they are unable to manage or control changes caused by cancer or normal life activities, they are in distress. Distress has become increasingly recognized as a factor that can reduce the quality of life of cancer patients. There is even some evidence that extreme distress is associated with poorer clinical outcomes.<sup>4</sup>

# Reaching out methods:

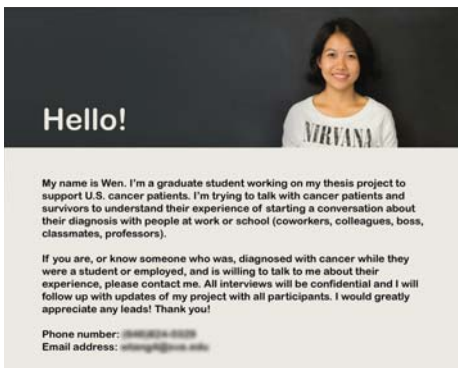


1. Volunteered in Fashion Fights

Cancer support workshop

2. Sent message to meet-up group

organizers

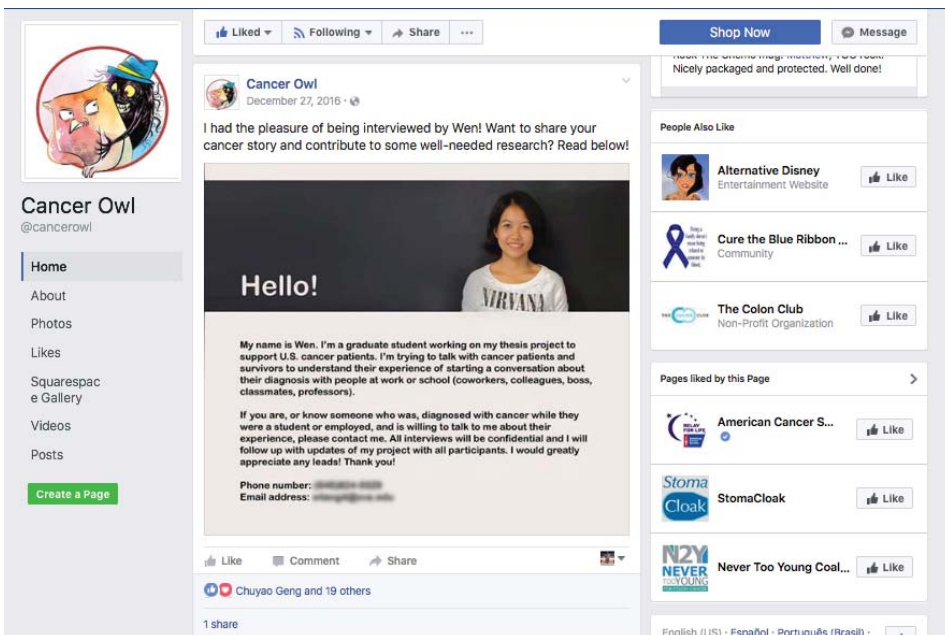


3. Posted reaching out message on

Facebook

4. Participated Caregiver Support

Group



5. I interviewed Matthew who is a

cancer survivor. He creates comic and

draws himself as an owl. "The comic

he creates has been able to impact

thousands and is currently being used

in cancer support groups and college

classrooms." After the interview with

him, I asked him for helping me post

my reaching out message on his face-

book page. Because of his help, I had

more opportunities to talk with young

adult cancer patients.

2

# ANXIETY & STRESS



## Question for myself:

What makes cancer patients feel anxious and stressed?

## Research:

Interviewed patients

## Narrowing down:

Target audience:

Young adult cancer patients

## Learnings:

- Cancer patients often feel stressed about the uncertain situation.

- Cancer patients often feel more anxious during the days after getting diagnosis and before starting treatment.

Because in this period of time, patients already know they have cancer which is a shock news, and there is no action they can take at that moment. "I

can't stop thinking it, which makes me really overwhelmed."

- Sometimes it's even harder for patients to break bad news with people than process the fact by their own.

3

# BREAKING BAD NEWS



## Question for myself:

Do cancer patients often feel stressed about telling people the diagnosis because they have larger social network than seniors and they have to mention the bad news many times?

## Research:

Interviewed patients and friends

## Learnings:

- For patients, sometimes it's hard to mention to people even once, because they are still processing the fact by themselves.

- Patients mentioned that there are different groups of people that they need to tell which is stressed. But they usually have a close friend in that group to be a point person to help them tell others and navigate the conversation between them and other friends.

- Compared with the "breaking bad

news" conversation, the daily life conversations between patients and their friends makes patients feel more stressed and overwhelmed. Because the conversations topic is always about cancer which constantly reminds them that they are cancer patients. And friends don't notice this issue because patients know they mean well and appreciate that friends are caring about them. So patients usually just say "Thank you!" to friends and don't mention too much of how they feel which makes this "problem" invisible.

4

# DAILY LIFE CONVERSATION



## **Question for myself:**

Do patients usually feel stressed of keeping talking about their disease during the daily conversation with people because they have to repeat the similar updating information to people many times?

## **Learnings:**

Young adult cancer patients feel stressed and overwhelmed in being constantly asking same questions about cancer and repeating answers in their daily conversation with peers when they initially are diagnosed with cancer.

## **Research:**

Interviewed patients and friends



**Why being constantly reminded  
of their disease causes more  
stress and anxiety?**

## Updating Information

When is your next appointment?  
Are you going to have chemo?  
Anything new?  
What's next?  
.....



Eliminate the  
repetition

## Showing Care

How are you doing?  
How are you feeling today?  
How is everything going?  
.....



Show care in a  
better way

- Young adult cancer patients have large social networks and it's tiring for them to repeat it many times.

- Young adult cancer patients don't want to be seen as fragile or weak, and be treated differently.

- People are trying to ask patients questions for showing care, but they are not really asking or saying something appropriately.

After getting diagnosis, patients who are still working or at school, they are facing the situation that when people find out that they have cancer, they care about the patient so much and would ask questions about updates of appointment and treatment. **Cancer patients told me that one of the biggest challenge is people ask the same questions and they have to provide the same update and tell same stories all the time, and "that is very tiring and exhausting".**

The questions that people usually ask when they talk with the cancer patient are for getting to know some **updating Information** or **showing care**.

5

# PRACTICAL NEEDS



## Hypothesis:

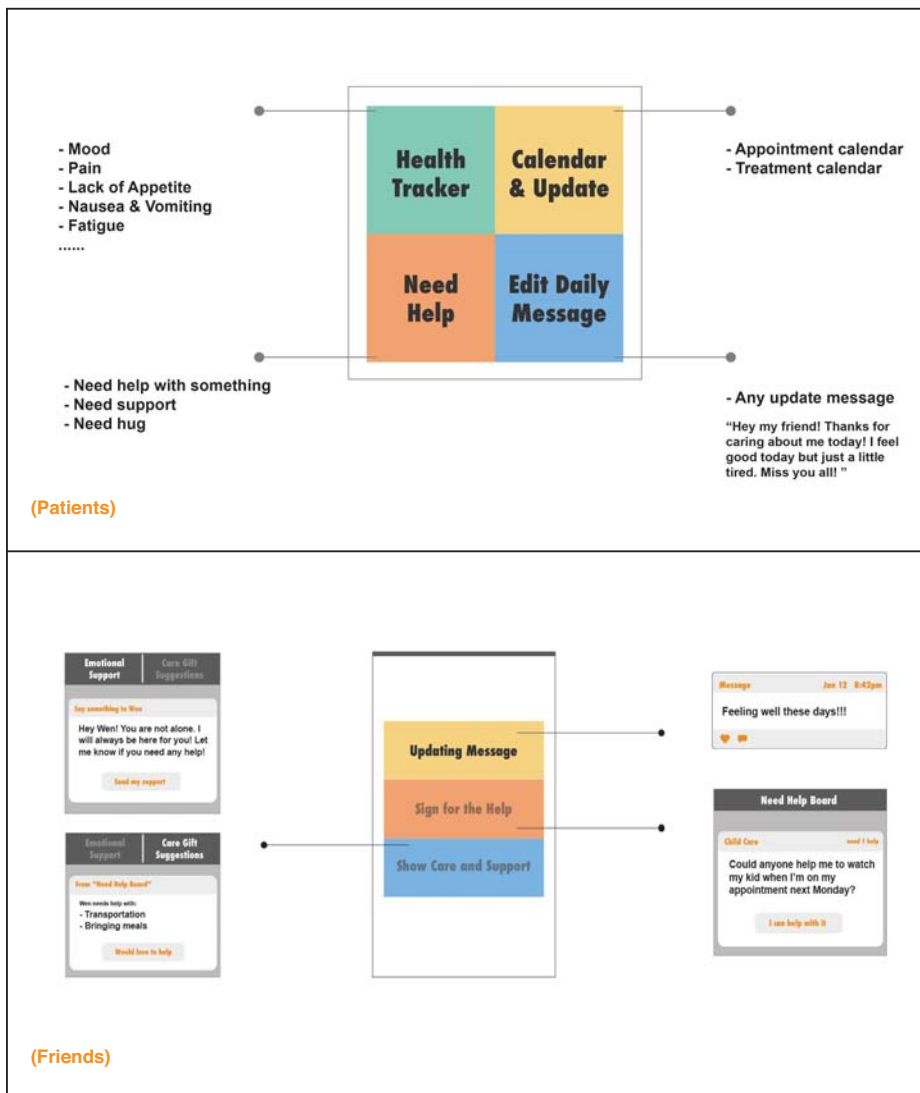
If patients regularly update their information and friends can better know the situation that patients are facing, the conversation about “cancer” will be not that much to make patients feel stressed.

## Learnings:

Young adult cancer patients feel stressed and overwhelmed in being constantly asking same questions about cancer and repeating answers in their daily conversation with peers when they initially are diagnosed with cancer.

## Research:

Did Prototype with patients and patient’s friends



I did the conceptual prototype with patients and their friends by showing them the two pieces of chart. The top chart was the one I showed to patients and the other one was to patient's friends.

I was trying to know if there was a platform having the four sections for patients to update, do patients feel it would help with their situation or not. And how patient's friends think about it.

## Learnings:

- Keeping posting update makes patients worry about over sharing.
- Patients need help with daily life activities the days after chemotherapy.
- Patients often have difficulties asking for help from people around them.
- It's easier for patients to receive the help and support from friends without asking for it.
- Friends want to help & show support but they don't know what to do.

# **The biggest take aways from the whole research process**

- A point person helps the cancer patient navigate or organize the situation and the connection with other people.
- Patients often have difficulties asking for help from people around them.
- It's easier for patients to receive the help when friends offer before patients need to ask for it.
- Friends want to help & show support but they don't know what to do.

# REFRAME THE PROBLEM



Young adult cancer patients who are in early stage of treatment process often have difficulties communicating about what they need with people who could offer help.

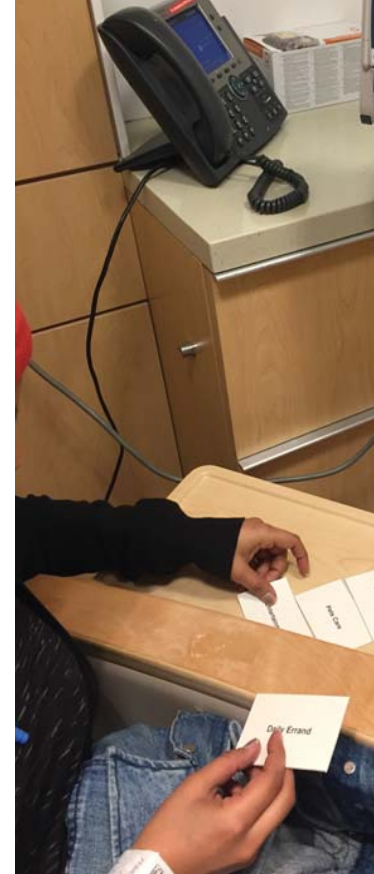
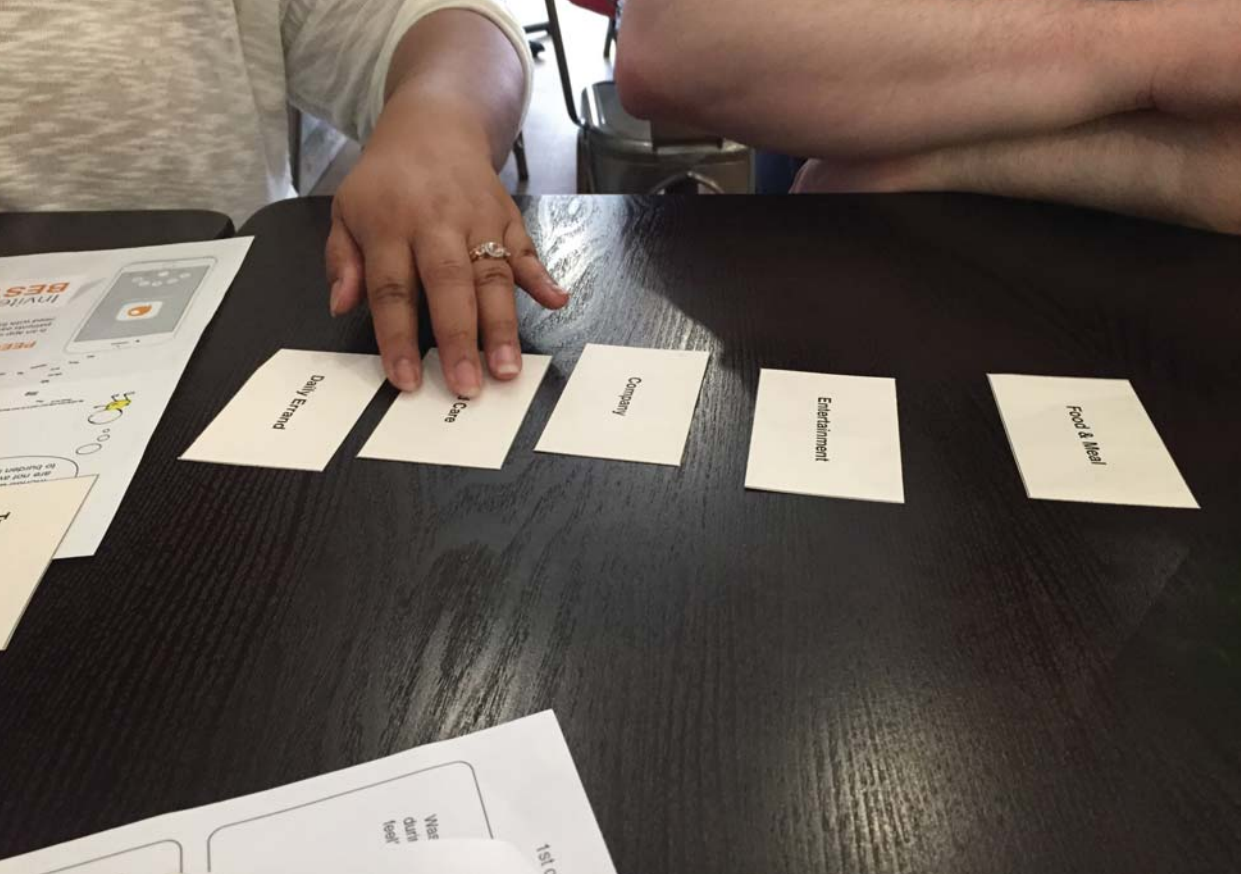


What specifically are the needs?



In order to understand the problem better, I interviewed patients, family members and friends.

And I was shadowing a patient from having chemotherapy to 3 days after chemotherapy.



# Card Sorting Activity

## Intro:

During the interviews with patients, I asked them to do the card sorting activity which helps me to better understand what are the specific challenges that they are facing in their daily life after treatment.

Each card represents a need that patients may have in daily life. Patients pick 5 cards that they need help most and put them in an order. Patients can also add their own categories.

## Learnings:

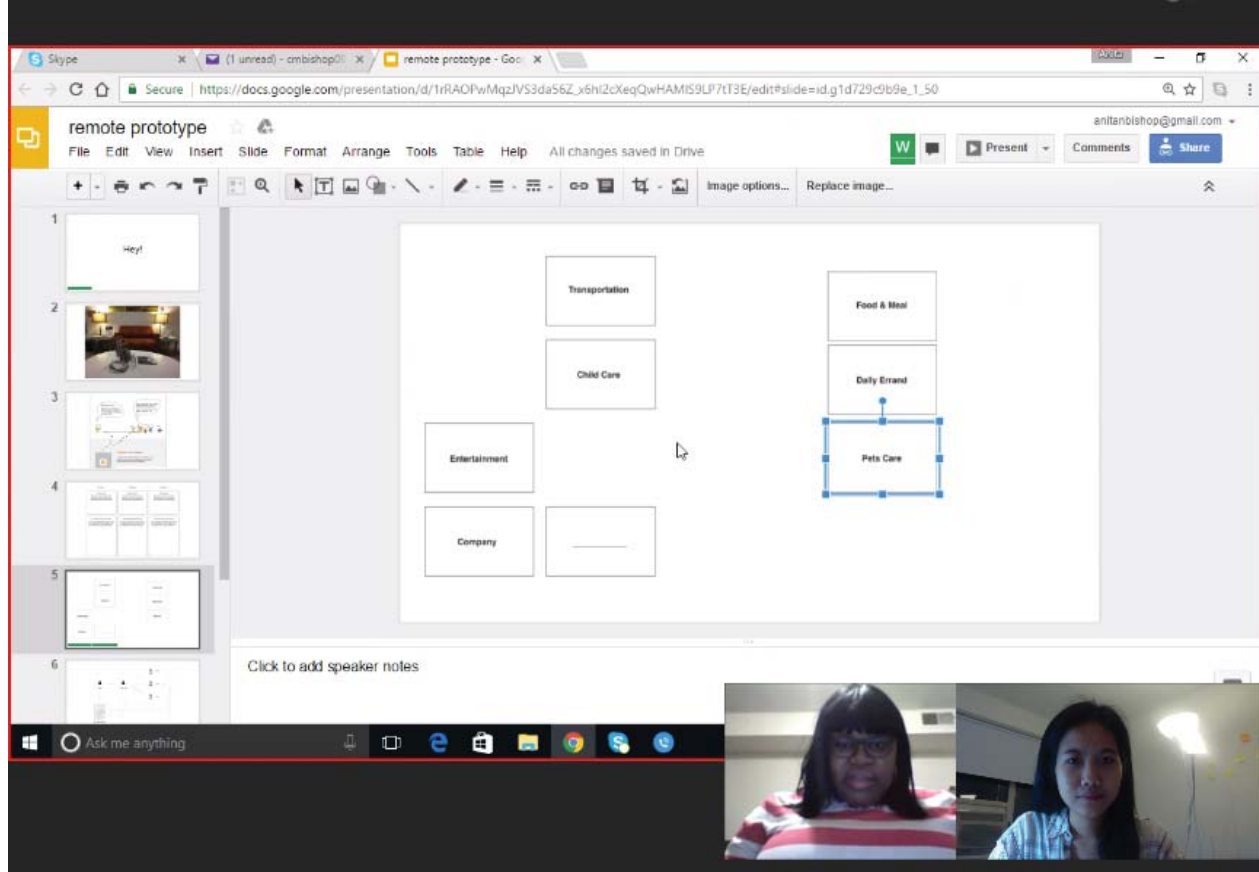
- During chemotherapy and few days after chemo, there is a lot of fatigue, weakness, nausea, dizziness, pain and sensitivity to cold. For some patients, it's even hard for them to get up from bed and go to the bathroom by their own. Patients need help with daily life activities like bringing meal, transportation, company, child care etc.

- Patients usually need help with practical needs like cooking, buying grocery, housekeeping because these tasks take more energy which they are not able to do when they have the side effects after treatment.

- Patients usually need help with emotional needs like having someone to be there with them, talk with them or just do their own stuff but physically stay with them to let patients feel they are not alone.

- When patients need help, they would ask for help from average about 5 people: their parents, husband or wife, relatives, and friends who they have many years friendship with.



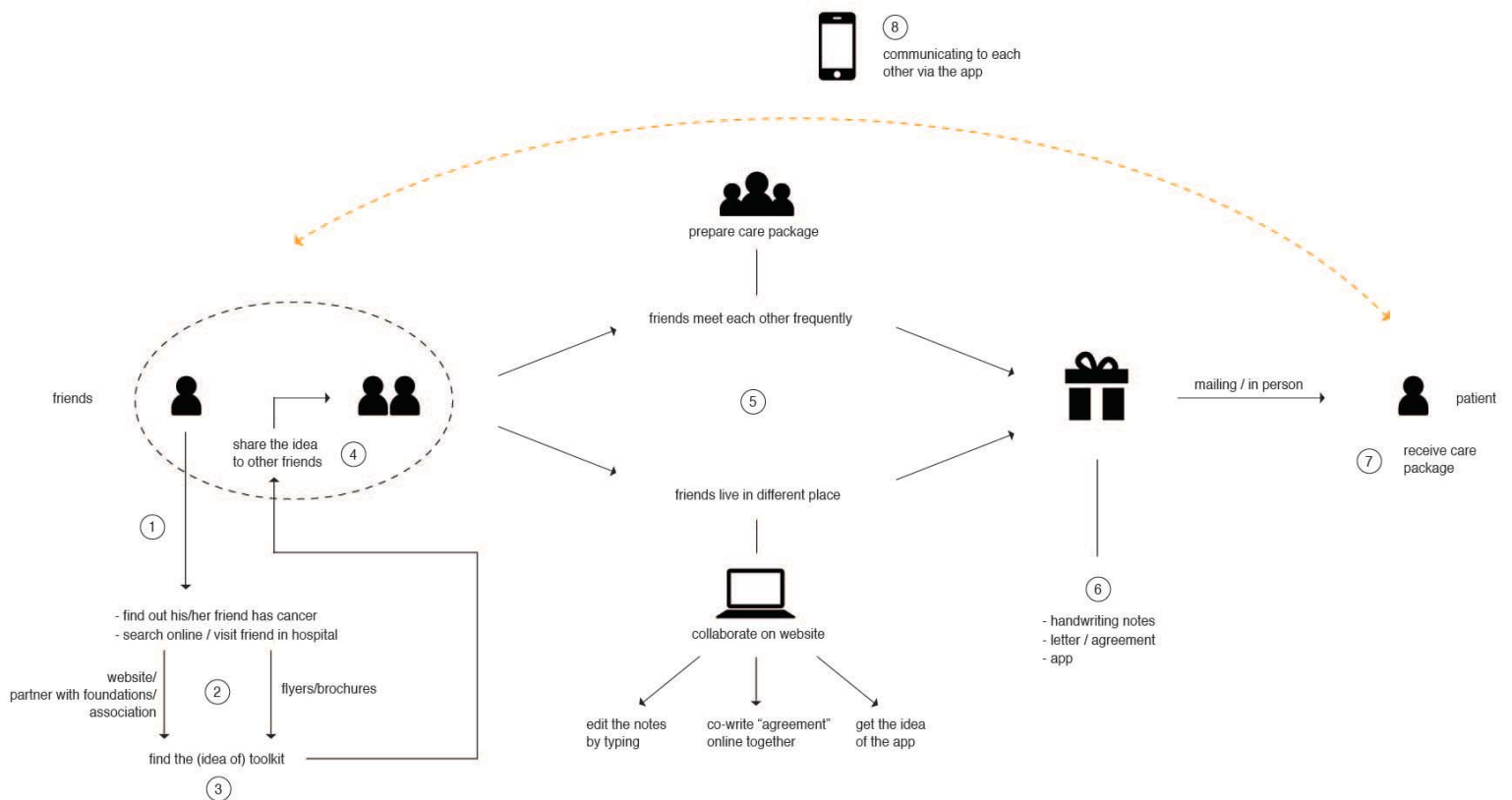


- Because the immune system is getting lower, patients have to spend their most of the time at home to don't have too much interaction with people which might make them sick. But patients want to feel connected with people.

- "Let me know if you need any help." It's a common conversation happened between patients and their friends. Friends care about patients and want to help, so usually when friends want to offer help and support and don't know what to do, they would say let me know whenever you need any help. Patient will be very thankful, but usually when they do need help, they too shy to make that call and say I'm having a really hard time today, can you cook me lunch? Even friends show that they would love to help, there is still a mental barrier for the action of calling someone and asking for help. And some patients mentioned to me that it's hard for them to ask for help because they are worried about relationship changing.

- It's tiring for someone who has cancer to tell all the friends what everything goes on and what are the practical needs. If the patient can depend on one person to do all the organizing and management of telling these people and getting them to help with practical issue. It would be very helpful. So the one network person needs to be telling all the friends.

# FIRST ITERATION



# How does the system work

① – ④

When a patient's friend first find out the patient has cancer, this friend may either search online for more information of the type of cancer that the patient has, or visit the patient in hospital. The friend can find the tool online or by seeing the flyers in hospital, then share the idea of care package with other friends.

⑤

If the group of friends can meet each other frequently, they could prepare the care package together physically. Or they can make it on website.

⑥

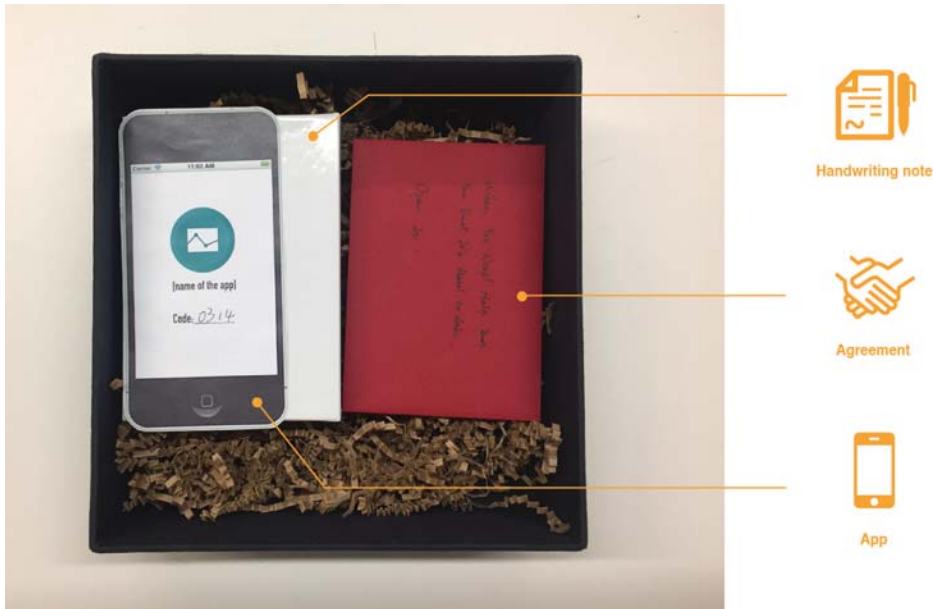
There are three basic elements inside of the care package:

- Handwritten notes (short caring message from friends)
- An "Agreement" letter (friends write a letter and say they are all willing to help and agree to build the support network for the patient)
- A card which has a short introduction of app.

⑦ – ⑧

Patients receive the care package and communicate with friends about the needs via the app.

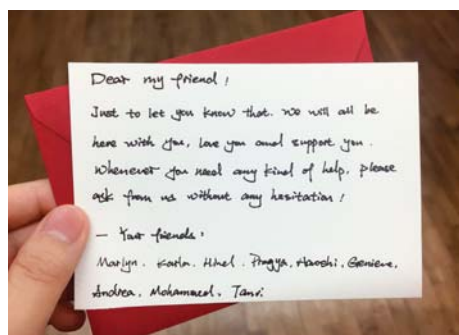
# What's inside of the care package



Patients often have difficulties asking help from friends because they don't want to burden anyone and they are not sure whether friends are willing or available to help. So the aim of having this care package in the intervention is to break the mental barrier for the patients to let them know this group of people are willing to be their support network.



Handwritten notes



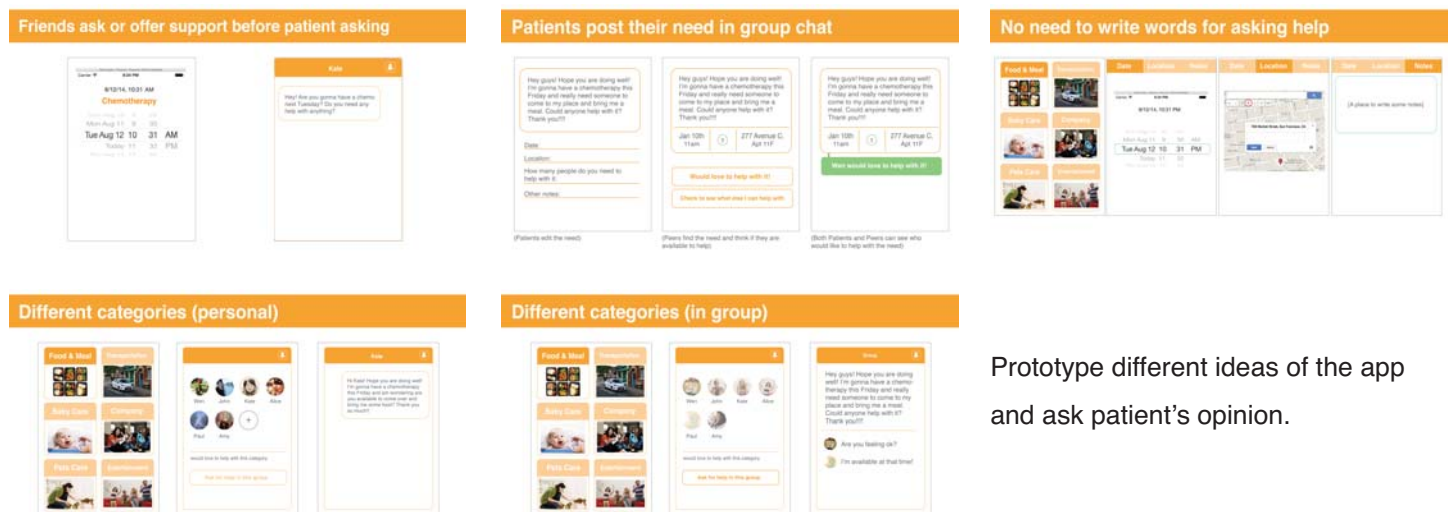
Agreement



A card of an app



I did the prototype with a patient and some of her friends. I showed the intervention system to friends and let them write down the handwritten notes and agreement. then I brought the package to the patient. After the whole process, I interviewed all of the participants.



Prototype different ideas of the app and ask patient's opinion.

## Learnings:

- Patients feel it's nice to have the care package, but the handwritten notes and "agreement" letter seems like very similar. And they don't want the "agreement" letter makes them feel like it's a contract. Because it's about friendship, it's not something should be related to transaction.
- Many patients mentioned that they would love to receive the care package by mailing. Because after treatment physically they not feel well and don't have enough energy to have people in their place and treat them.
- Patients like to have categories in the app because it helps them know who would love to help with what specific kinds of need.

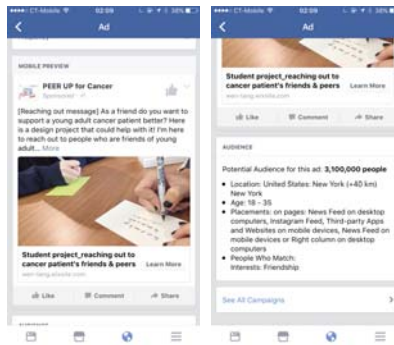


**In order to look for more  
“cancer patient’s friends”  
as prototype participators.  
I have tried these following  
ways to reach out.**



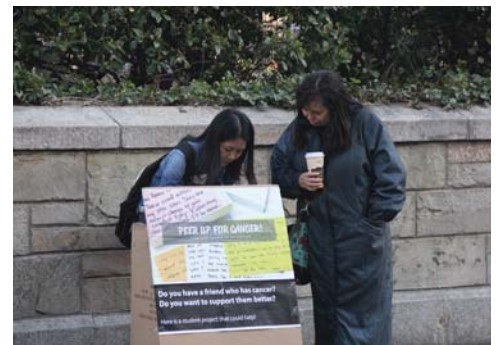
Poster:

I printed posters and put them in SVA, Pratt, NYU, Parsons, Pace university and New York Film Academy buildings



Facebook Ads:

Post an ad on Facebook



Interception:

I also tried to stand in the Union Square in Manhattan and hold a board with the introduction of my thesis project to look for participators.

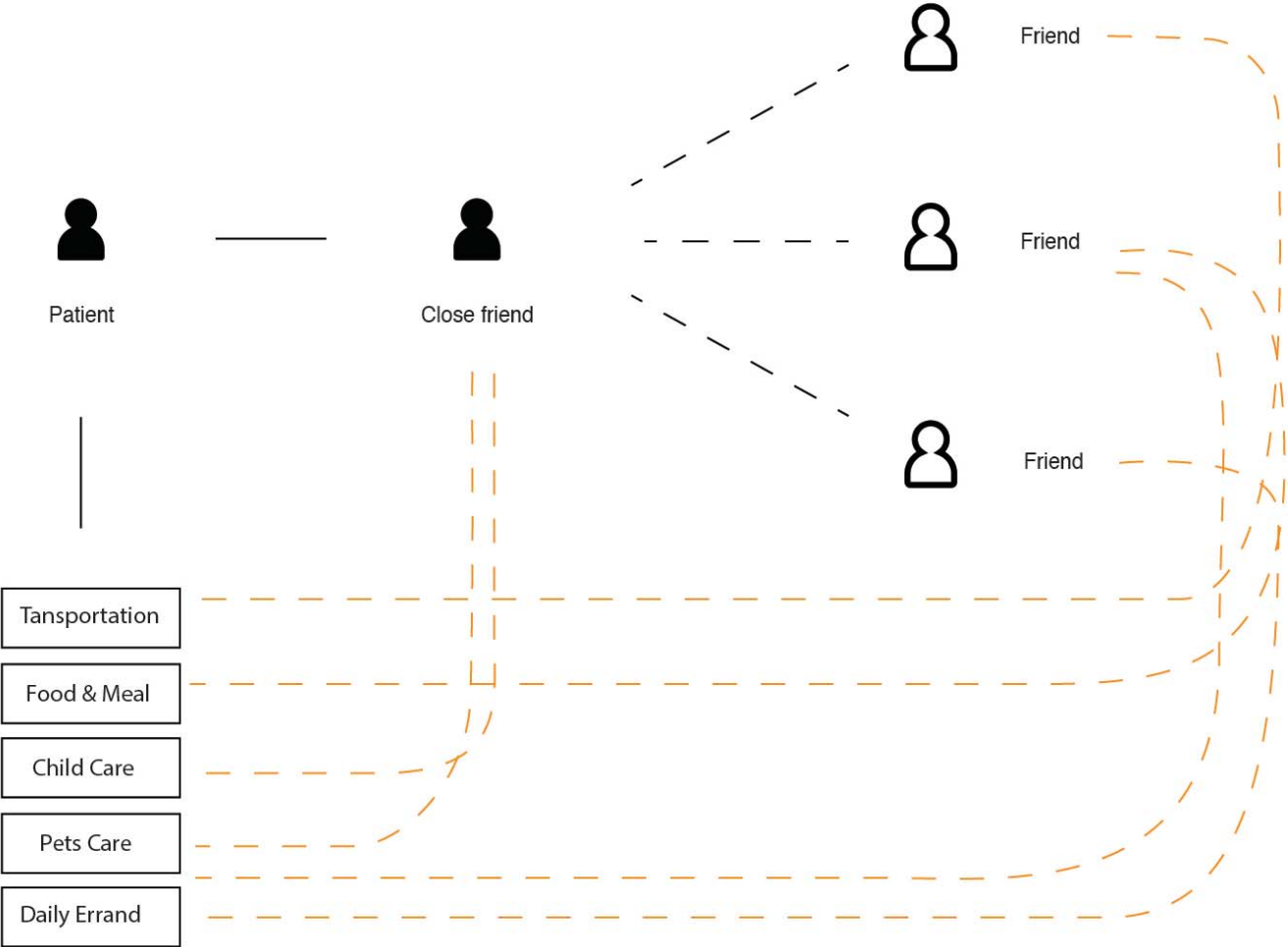
I have two assumptions for the reason why I can't find the "cancer patient's friends" to participate:

- People are concerned about their friend, the cancer patient's feeling and not sure if the patient would like them to participate this research process.

- When I had conversation with cancer patient's friends before, I found there is a need that friends want to help the patient but don't know what to do to help. It's a need but the need may be not strong enough to let friends make the action to start this intervention. It's a risk for the intervention.

**Then I made a pivot -**

# FINAL INTERVENTION





# Hypothesis

If patients receive the support and help easier when they feel vulnerable, they would feel more emotionally and socially supported and can get better recovery from treatment which leads to better physical and mental health outcomes.

If patients can ask for help from their friends without feeling they are interrupt others or add a burden to someone, it would be easier for them to ask for help when they feel vulnerable after chemotherapy.

If friends ask about or offer specific practical support before patients ask for it, it would be easier for them to ask for help when they feel vulnerable after chemotherapy.

## How does it work

Once a patient starts using it, he or she can invite one or two close friends to be a point person to support them and also invite more friends to join and help with the challenges.

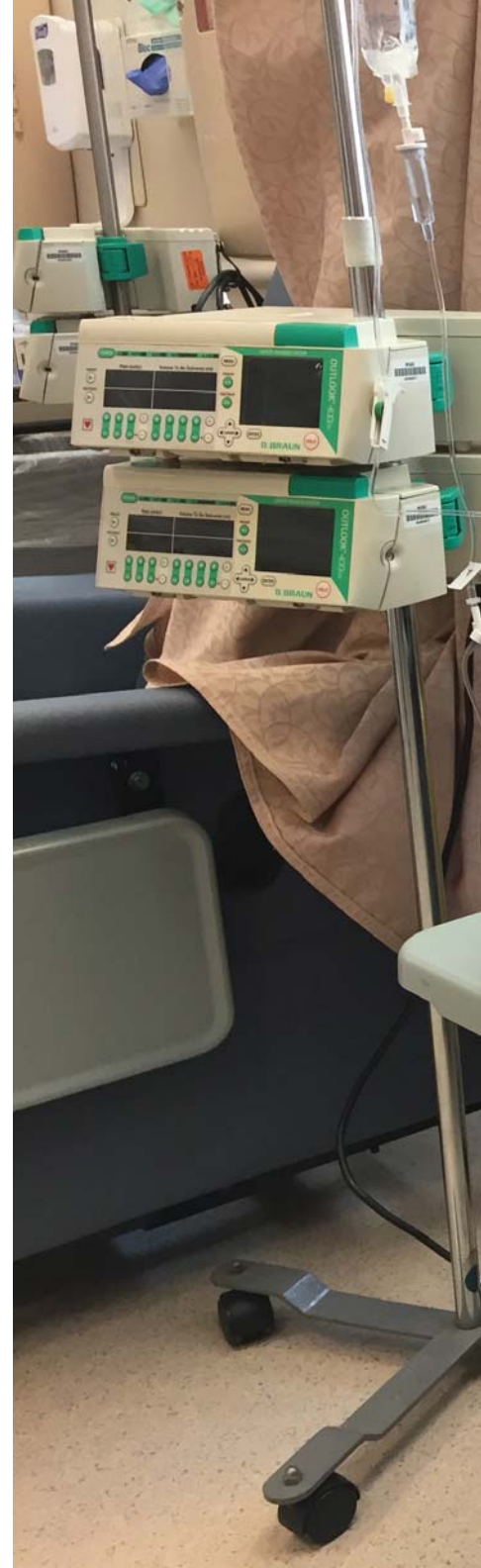
If patients are going to send a message to invite the close friend join the network, what is the message that they want to send to them?

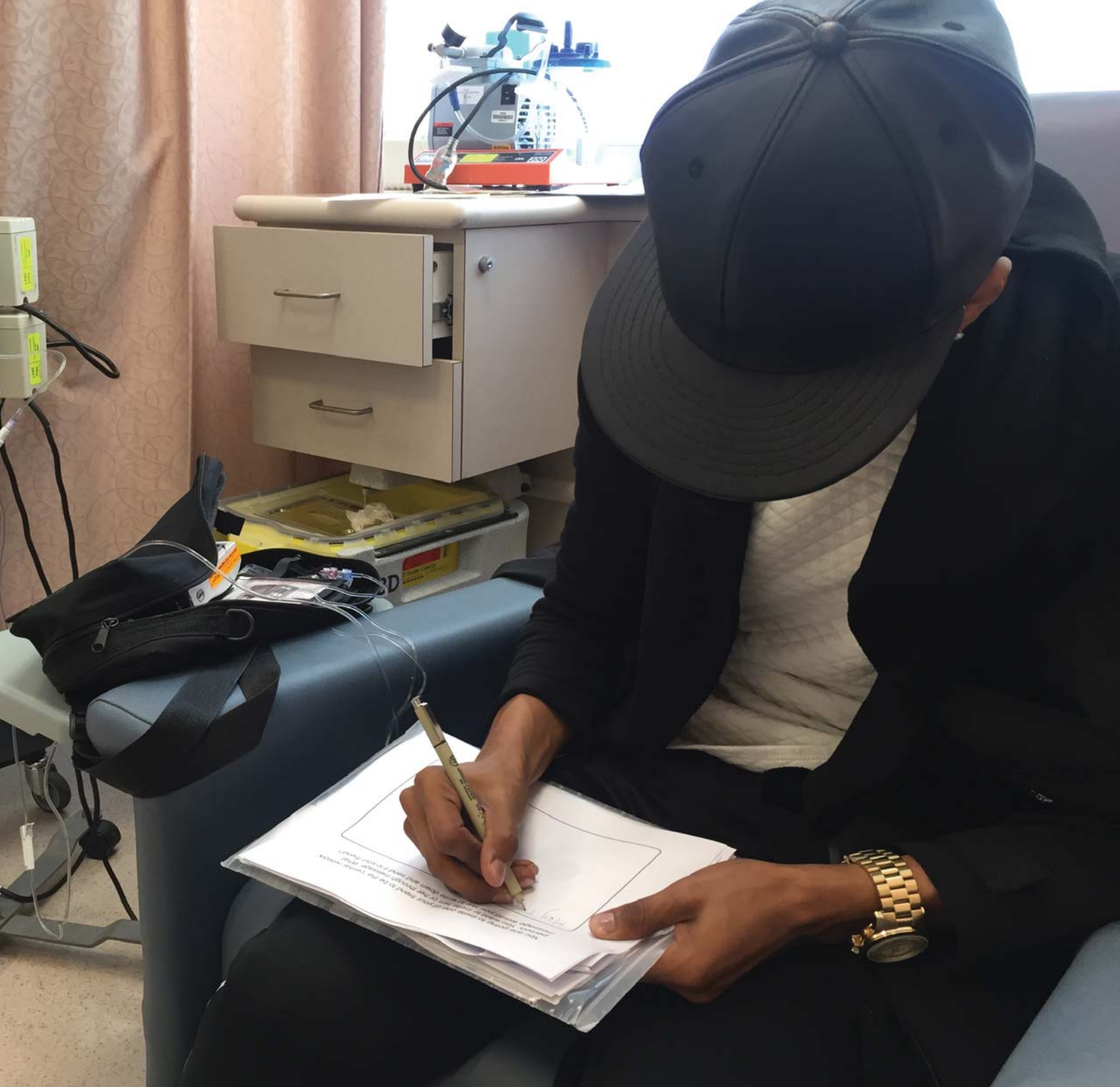
You are going to invite one of your friend to be the "central network" person. You want to invite him or her through message. What message would you like to write down and send it to your friend?

Hi, Karla! Hope this message finds you well. So as you know I'm starting my chemo sessions and I was just wondering if you would be able to ~~also~~ help me during chemo? I think I may need help w/ some stuff. ~~also~~ Also, it would be great to have a small group of friends that I could ask if you weren't available. Do you think you could coordinate that for me?

Hey TNGR's This great New App that you can download and can help me out and support me in things I need help that I can't do alone.

Thank you for being there for me. I need help with this ~~time~~ situation. Would you be willing to help me?





## Activity - Message of Inviting Friends

During the interviews with patients, I asked them "Who would be the person that they want to invite and what message they want to send to this person?". Then I asked them write down the message.



Get well.  
Hang on / your strong you  
can do it.



Funny videos  
animal videos

Funny snapchat  
photo

- a song that  
we both like  
- music they like

calling them  
through FaceTime  
just to say hi &  
see how they're doing



You've got this. You've done  
amazing this before and you  
can and will beat this. I'm  
always here for you. ♡





In order to understand what kinds of message patients would love to receive from friends during the days after treatment, or what kinds of message makes them emotionally feel better and feel more connected with people. I asked them to role play - imagine they are cancer patient's friends and want to send a message to the patient during that time, what would they want to send?

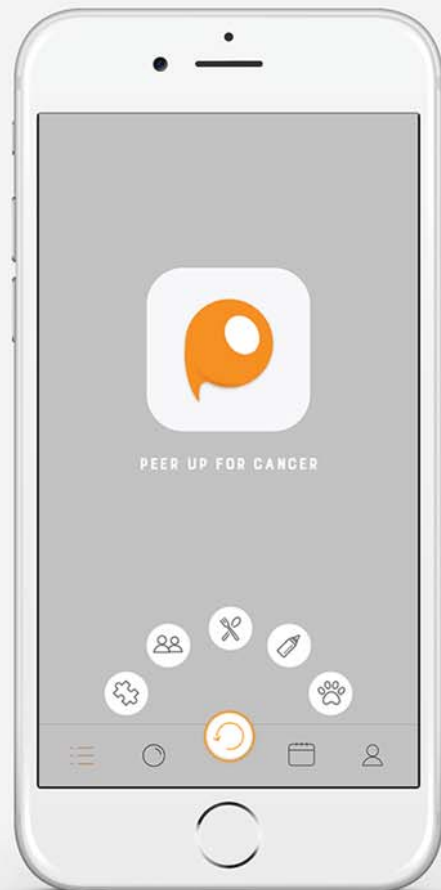


## Learnings from Activities

- The point person that patients choose is usually their best friends or family members like cousin, sister, etc. They have strong relationship with this person, and this friend would usually offer help before patients ask for it. Some patients mentioned that they would love to keep this network as small as all of the friends in this network are very close to them so that they won't feel vulnerable when they come and help.
- Patients would love to receive delightful and funny message because this could distract their attention from physical uncomfortable feelings and have the sense of cheerfulness and being supported.
- Some patients mentioned that they want to be seen strong and be encouraged.

# PEER UP FOR CANCER

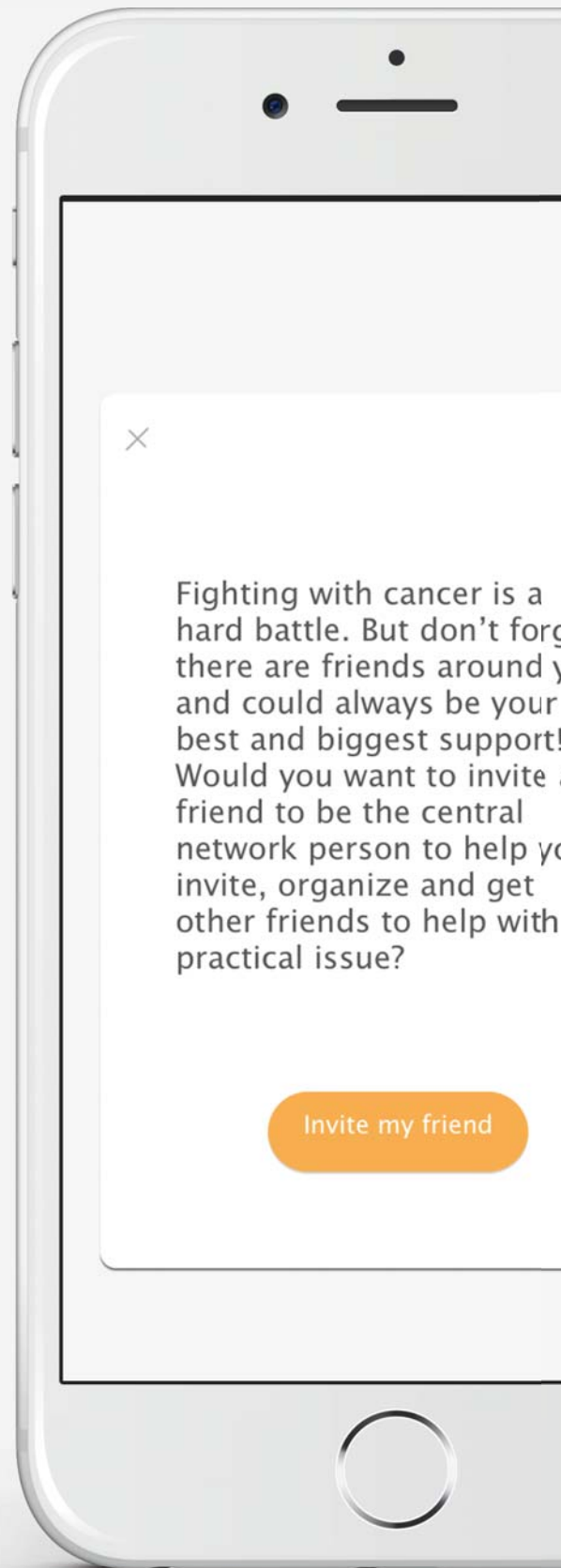
It is an app to bridge this gap between the patient's need and their friend's desire to help.



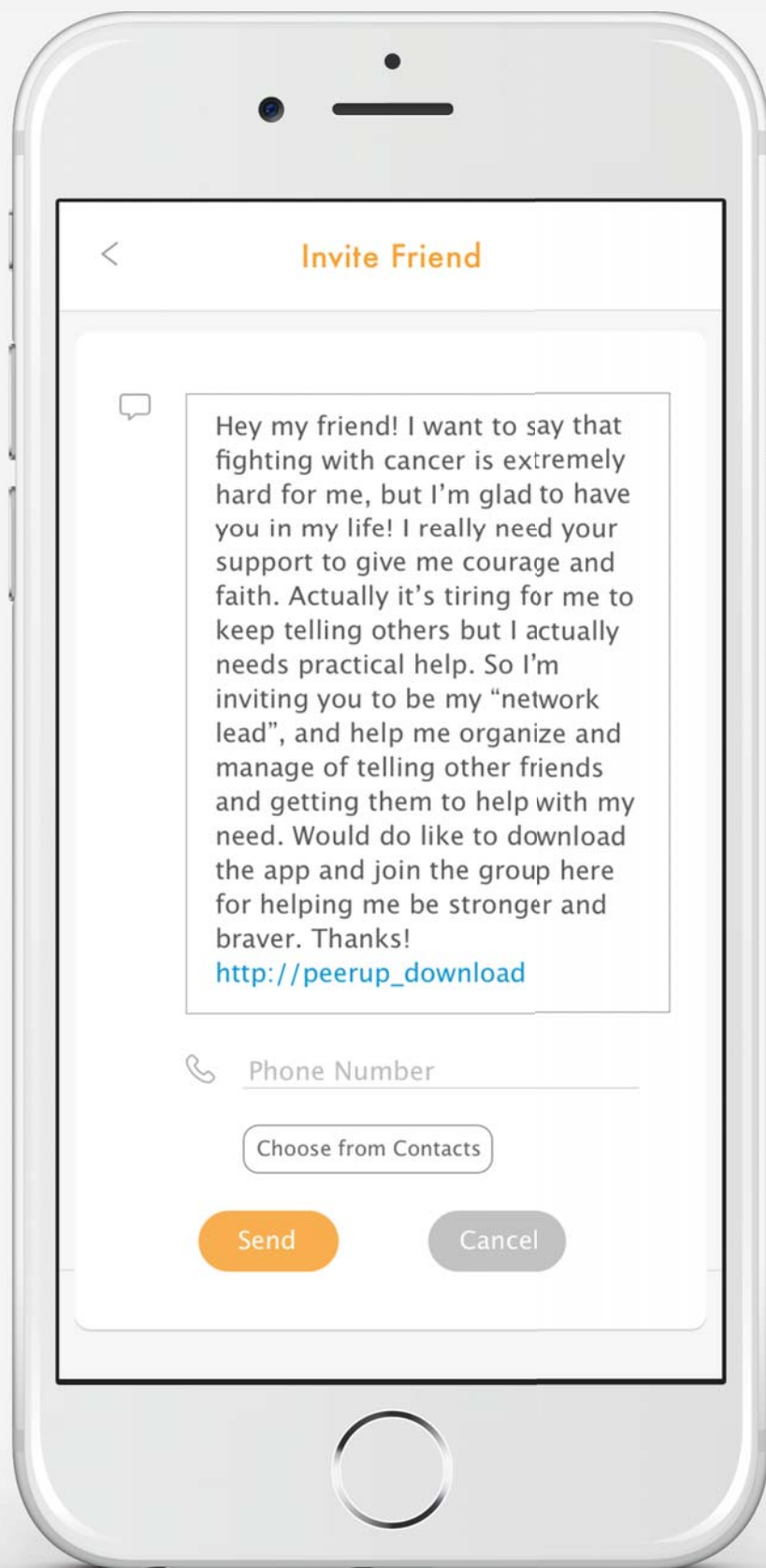
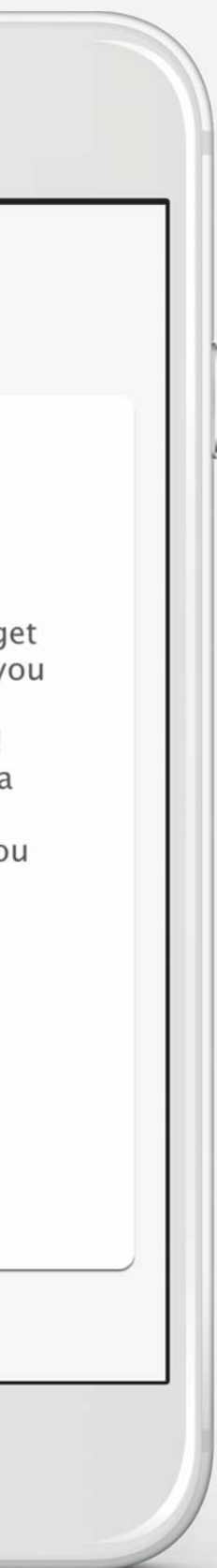
# Download & Invite Friends

When patients download PEER UP, they would get a notification from system to ask whether they want to invite friends to join the support network.

Patients can edit the message to the person that they want to invite.





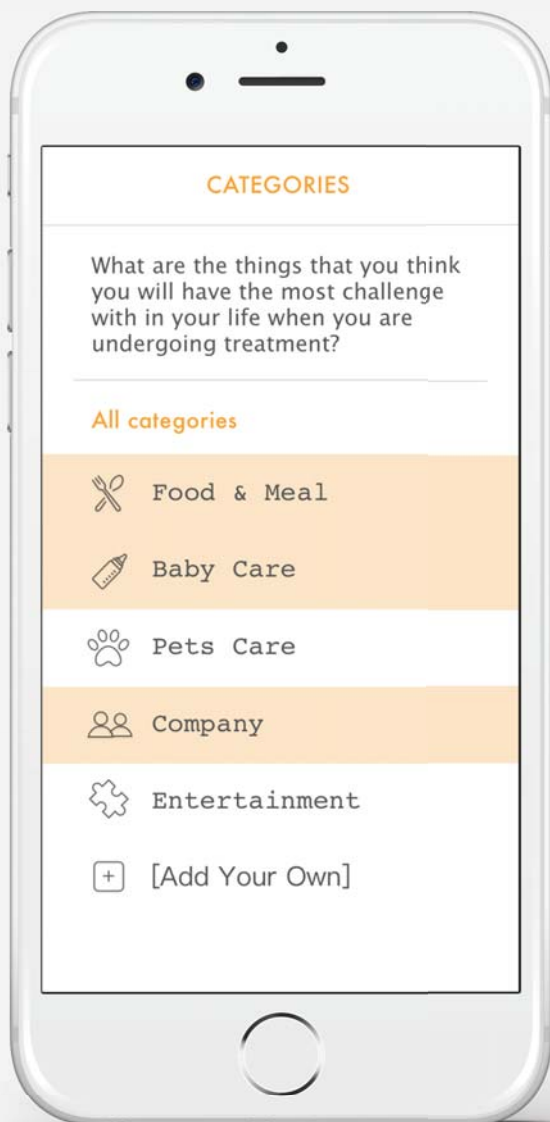


# Set up Categories

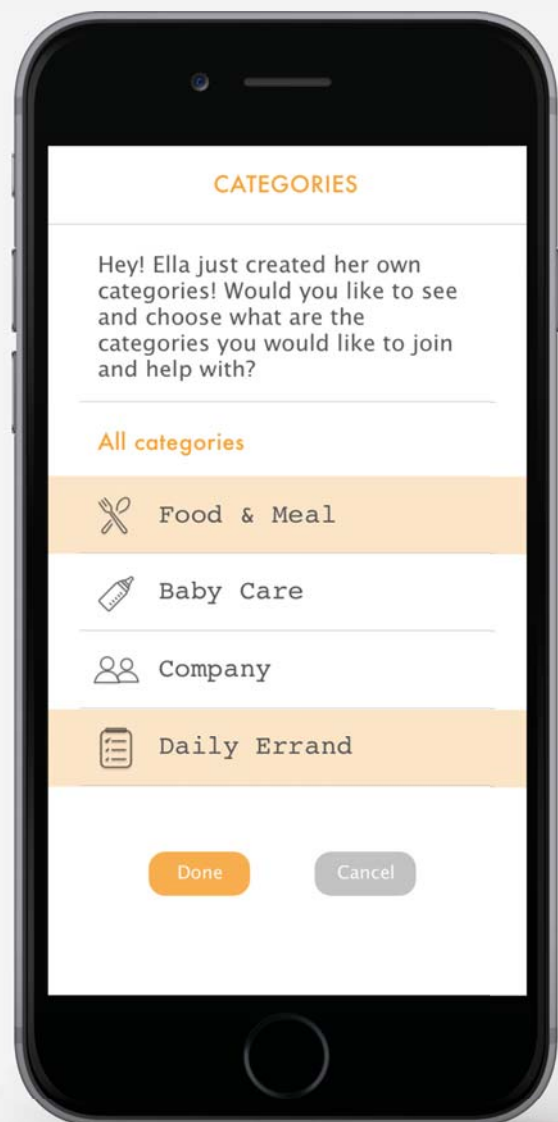
Patients can create their own categories based on their needs in the daily life after treatment.

When patients set up the categories, friends will get notification that to let them know they can choose which categories they would love to help with.

For patient's view

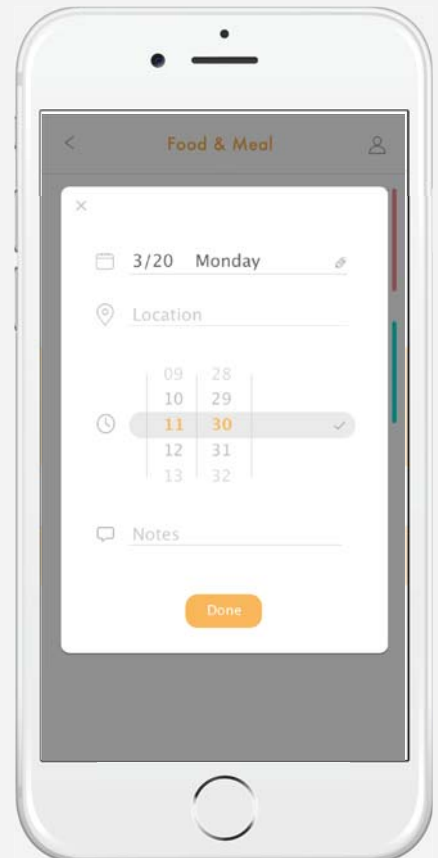
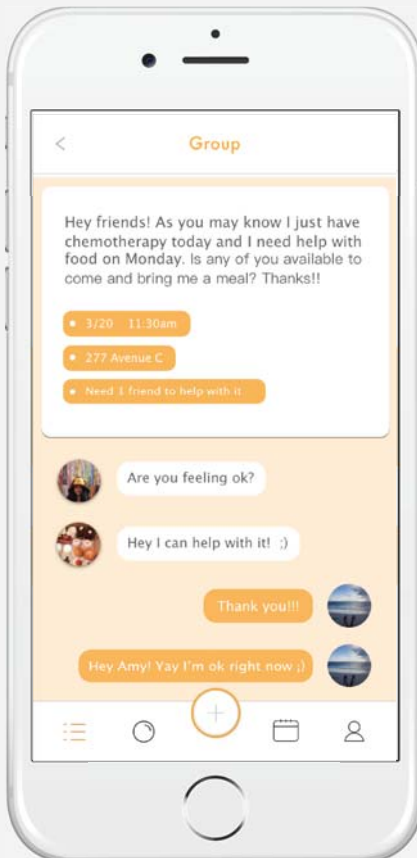
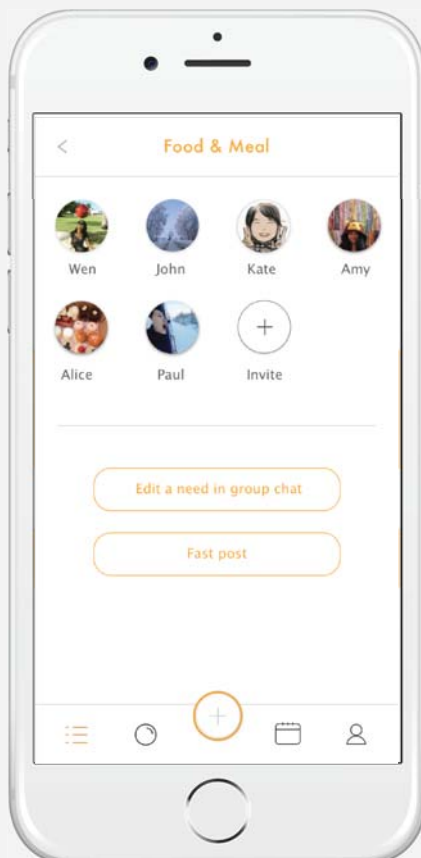
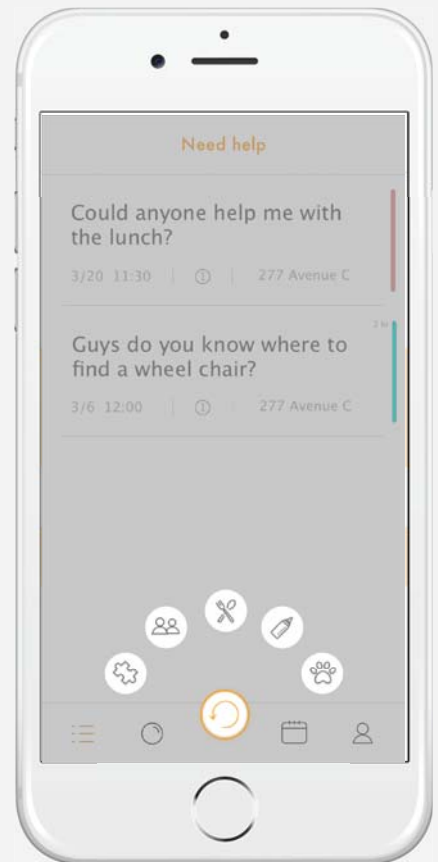
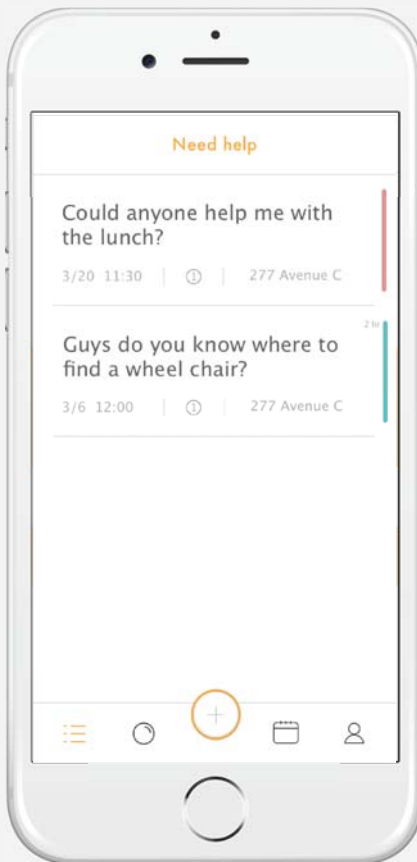


For friend's view



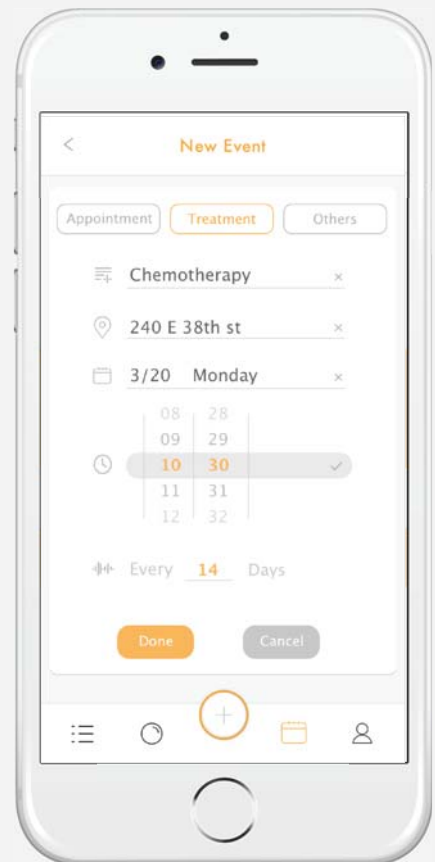
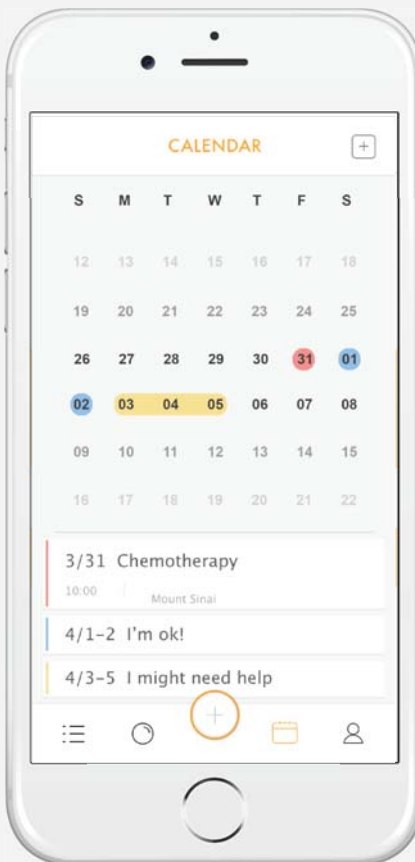
# Post Needs

When patients need help with a particular category, they can see who are the friends would love to help with this category. Then they can choose to send an individual message to a friend, post a need in the group, or make a fast post which they don't have to edit or type any word. They could only set up the date, time, location or maybe some notes.



# Calendar & New Event

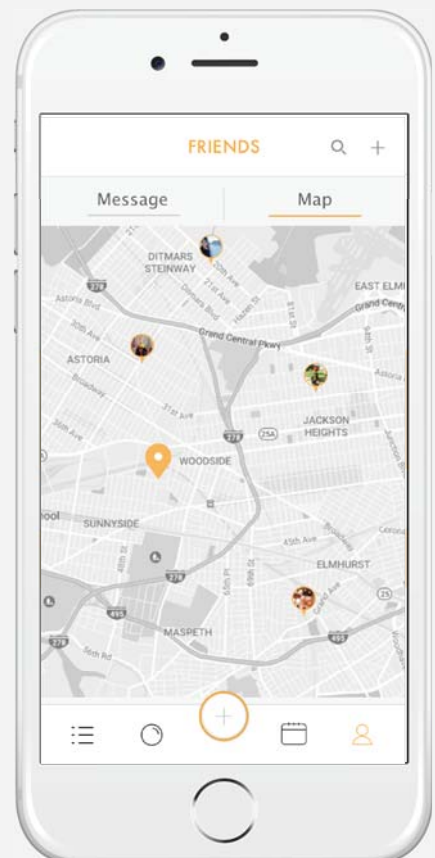
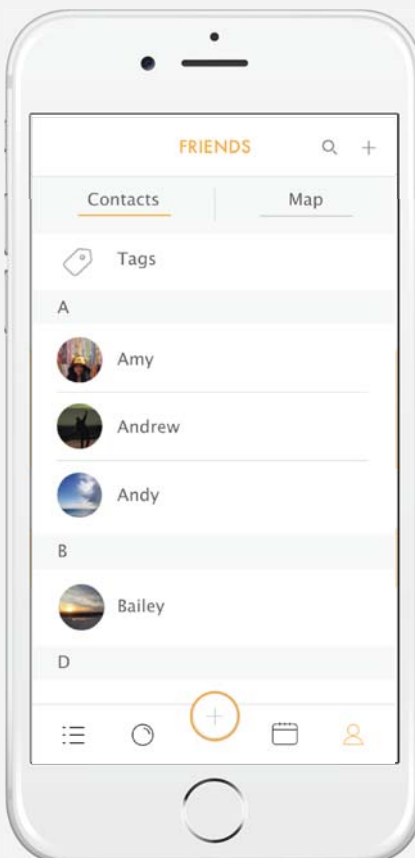
If Patients want to share their calendar with friends, friends can know in which day the patient will have treatment, and in which days the patient may need help. It could help patients pre-schedule and easily organize the situation and communication with friends.



# Contact

Patients can use Tags to manage different groups of friends.

If friends would like to share the location about where they are living, patients can know from the map that who live closer to them. It may help patients to decide who is the person that they can reach out when there is a need in a particular place.

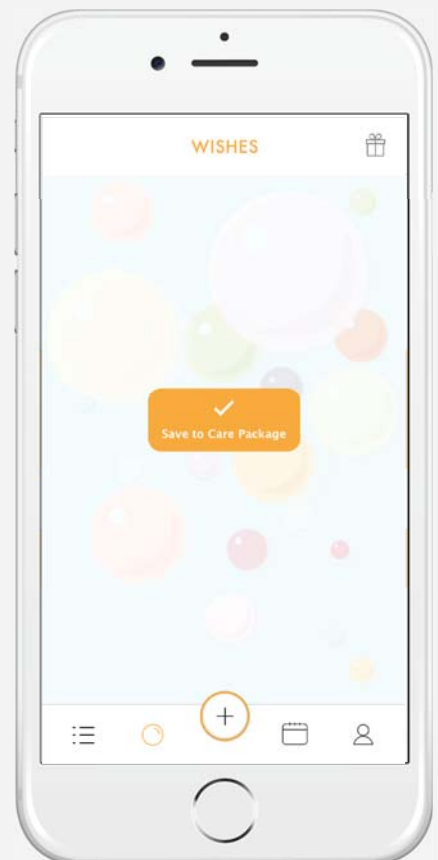
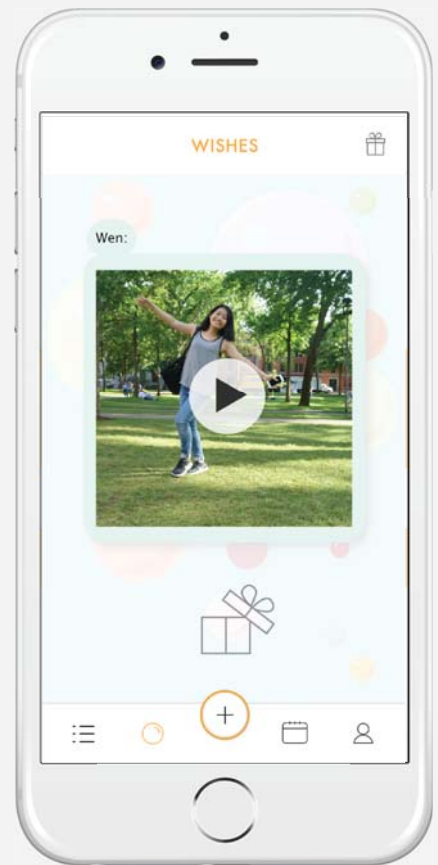
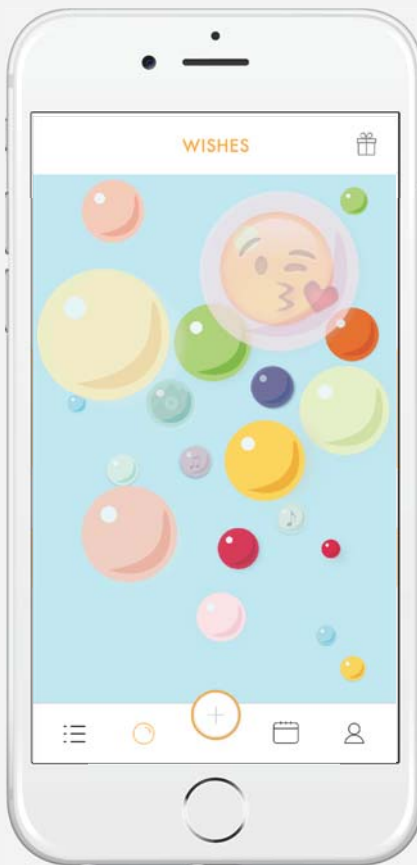


# Caring Message

Each “bubble” has a caring message inside which was sent by a friend.

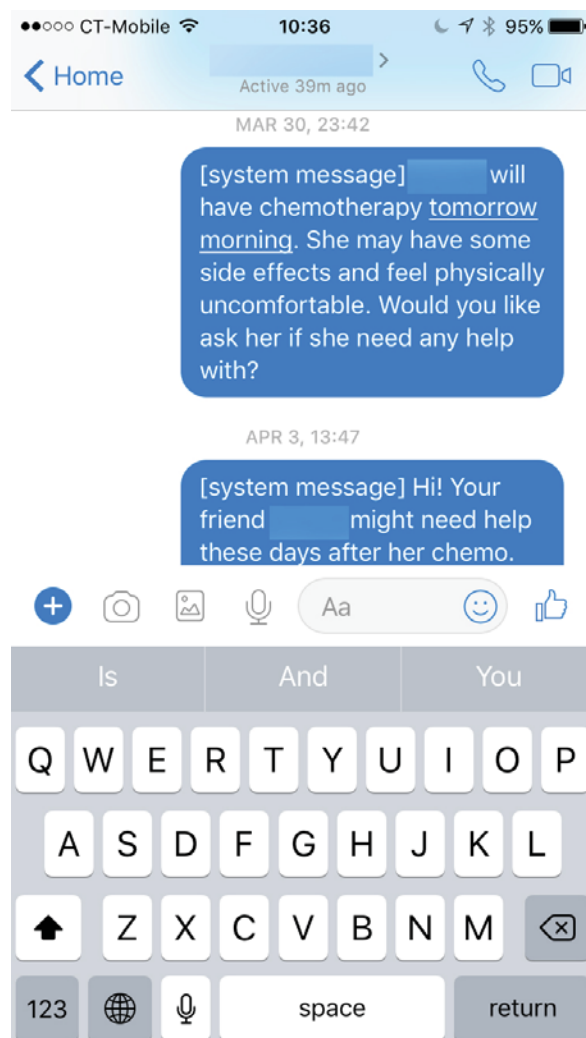
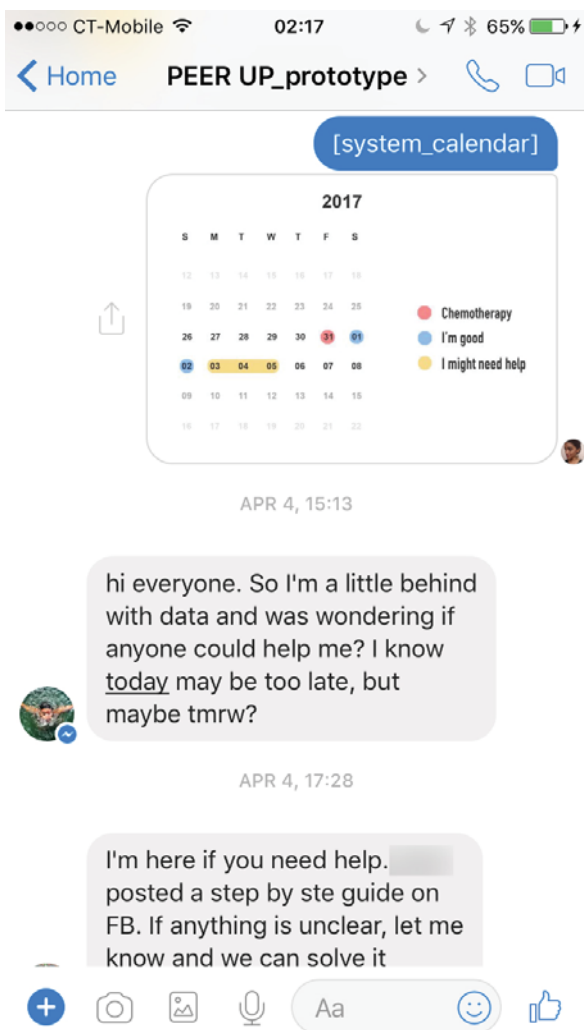
Message could be a funny video, image, emoji, simple words, etc. After seeing it, patients could swipe down to save the message in “care box”, or swipe up to delete the message.

The bubble on the screen is always new message. And after seeing it, patients no need to reply or respond on it. This is for patients after treatment who want to connect with people and receive some caring message but don't want to feel that they have to respond on those message.



# Prototype - Messenger Group

Then I did a prototype with a patient and her 9 friends. I created a messenger group and let them all join in this group. It was a one week prototype and was started from the day before the patient having chemotherapy. I was trying to make the group functioning more similar with the app that I'm designing.





# Prototype - App Demo



## Learnings:

- Patient: It will be a risk that patient post a need in the group but friends can not help with it, and also could be a barrier for patient to ask for help again. In the prototype the similar situation happened that patient asked if anyone could help her find a wheelchair for attending an event, though friends cannot really find one for her but people would like to provide ideas or resources to patient. And the patient feel thankful for it.

- Patient: Instead of have many friends involving in the group, the patient would love to have a smaller group which has only few her very close

friends. More comfortable

- Friends: Friends mentioned that if there is a need that the patient posts but they are not available to help, they may feel guilty and ashamed. They hope there is a way to let them say I can't help in a polite way. And the communicating way especially language of this "system" helps.

- Friends: It's better to send the notification to people few days before, because people have their own schedule, and it's better for both patients and their friends to manage the situation advanced.

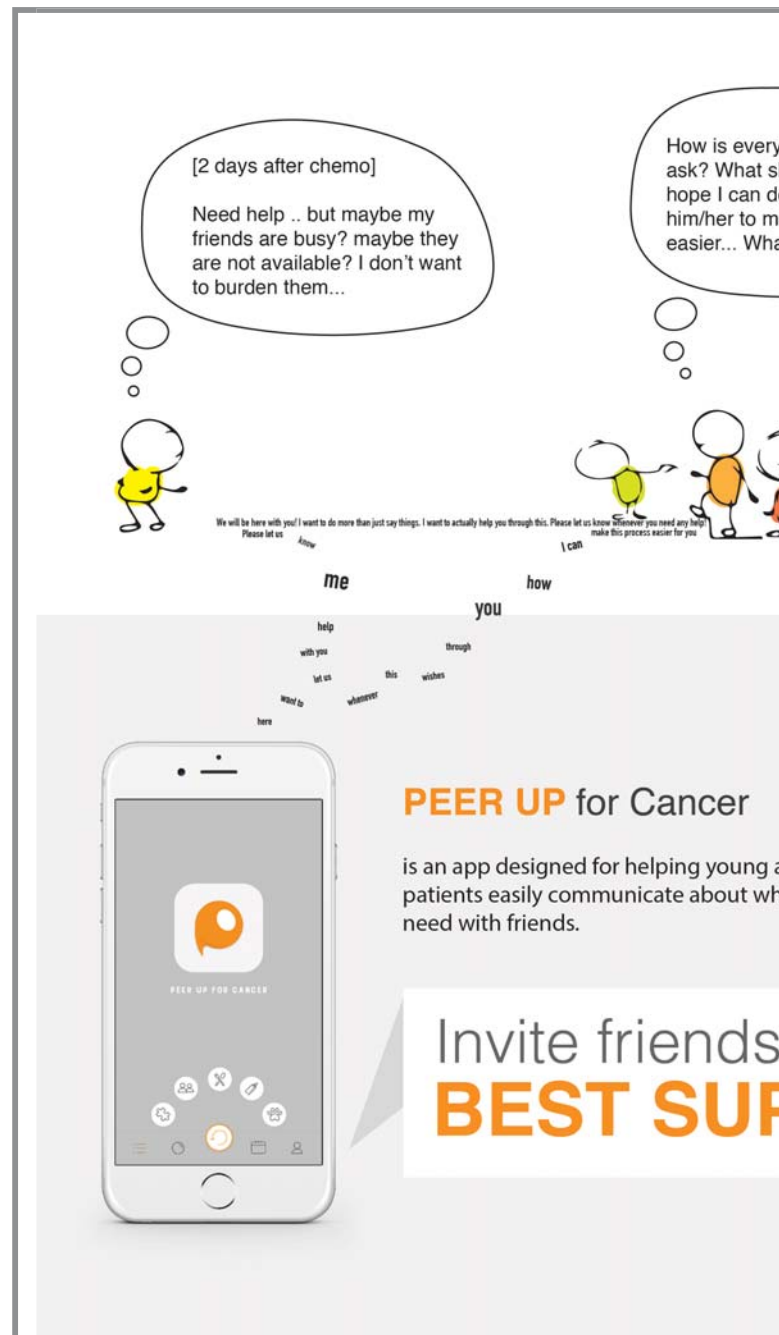
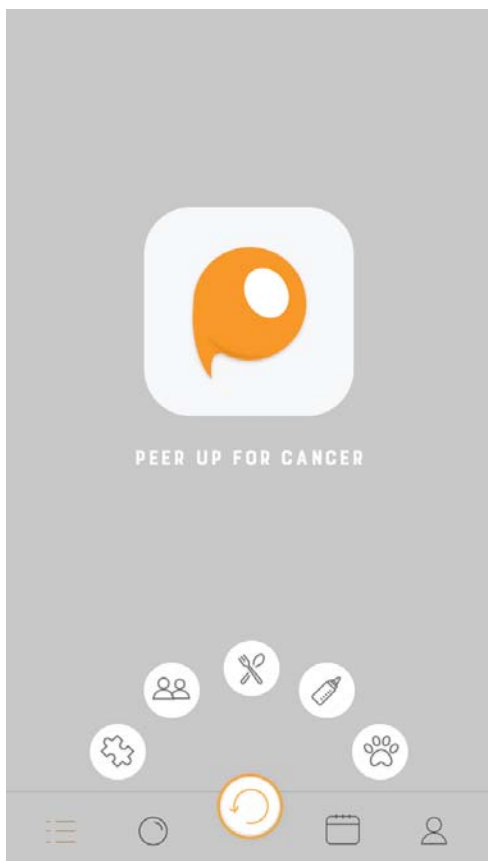
- Friends: It's good to have a place to check on her and know how everything goes. Because sometimes friends don't want to text patients and ask them "how are you today?" frequently. They are worried that patients probably too tired and they don't want to be bothered too much.

- Friends: Prioritize the needs would be helpful because they want to know what patients need help most, and if they can not help with the need, there is the place to know what else they can do.

# BRANDING



icon





What's going on? Should I  
say something? Should I  
say something for  
the life a little  
at can I do?



adult cancer  
that they

to be my  
**SUPPORT!**

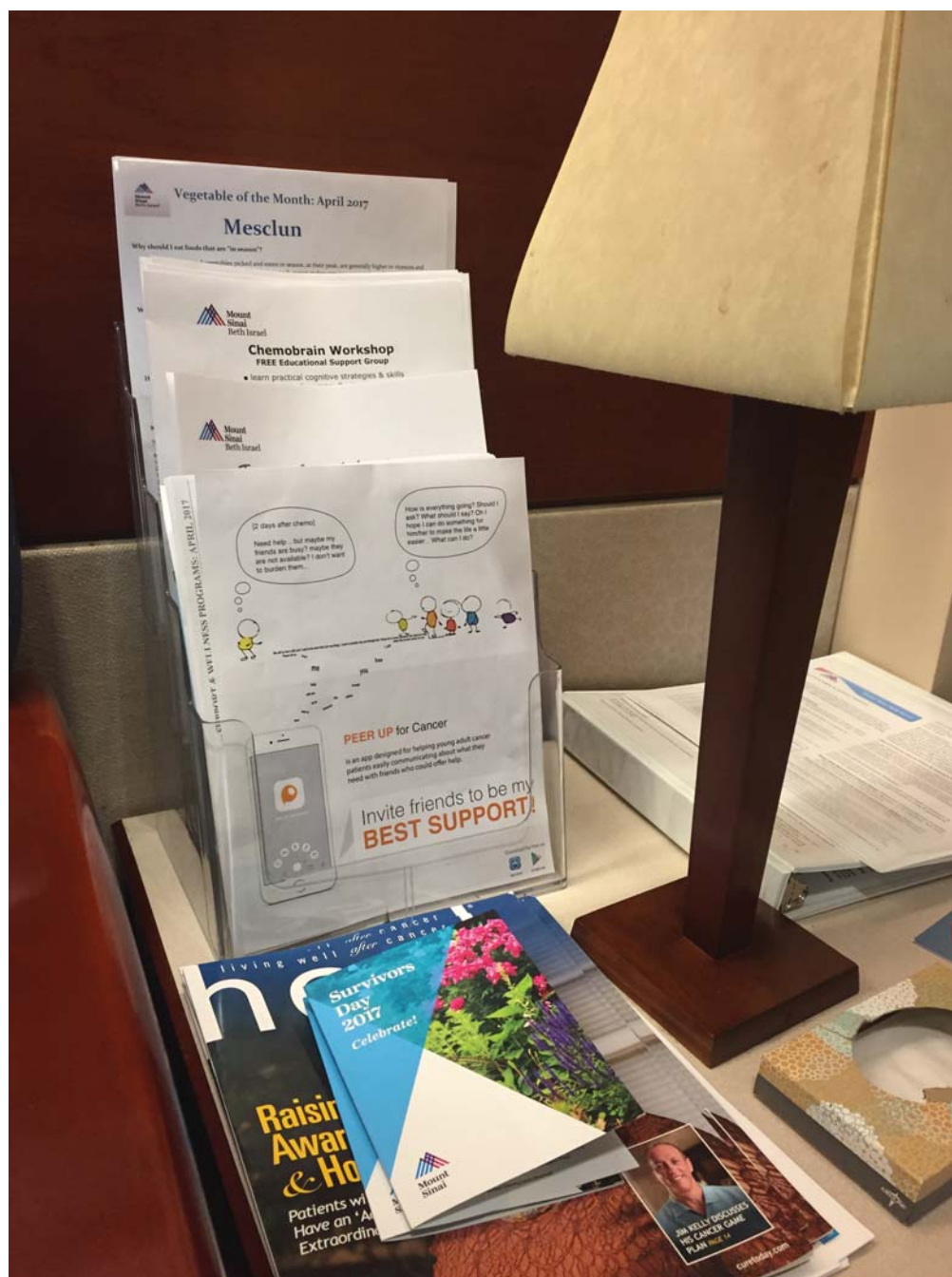
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Long Term Goal ➡

# THEORY OF CHANGE



Design Intervention ➡

Improves cancer patients physical and mental health outcomes

Improves mental health outcomes

Improves physical health outcomes

Prevents inefficiencies in  
chemo treatment

Patients can get better  
recovery from treatment

Reduces feelings of loneliness /  
isolation / stress

Patients can have good rest

Patients don't need to force themselves  
with some daily life activities which  
they won't be able to do

Patients feel more emotionally /  
socially connected with supported  
by their circle of friends

Practical needs get met more  
easily with less distress

Keeps the connection with  
friends and outside world

Patients receive the support and help  
easier when they feel vulnerable  
(emotionally / physically)

Has a social  
support system  
built by friends

Patients ask for help without  
feeling they are interrupt others  
or add a burden to someone

Friends ask about or offer  
specific practical support  
before patients ask for it

Friends express that they are  
willing and able to help with  
the needs patients have

Friends better understand patients'  
situation and know what kind of  
needs patients may have

General knowledge  
about cancer

Get to know some  
updates from patients

# NEXT STEP



I would love to continue prototyping, testing and getting to know the feedback from patients, friends, family members, social workers, etc.

For example, the intervention was focusing on the communication between patients and their friends. But during the prototype, I found that some patients choose their siblings or cousins to be their point person. So I want

to figure out is there any difference between the point person is patient's family member or their friend.

During the prototype, many patients asked me that "Is it gonna be a real app? Are you going to make it?" They said if this app is real, they want to use it now! I was so glad to hear that and also considering to try to get the app developed.

# LEARNINGS



To be successful, one needs to ...

Work very close to the audience

Ask the right questions

Keep testing and prototyping with audience

Be flexible

Be brave

Be nice and a nice listener

And there is always something we can try before giving up

# THANKS



I really want to thank to all the cancer patients, caregivers, the social workers, and people who participated and helped me with my project. Especially the patients who shared with me their stories and experience so openly and helped me to understand the situation and whole current system.

Thank Cheryl, Tina and Miya for guiding me during this entire year and giving me good suggestions. These not only helps me for the thesis but also in my future work. Thank to DSI faculty for all learnings in this two years.

Thank all of my lovely classmates and friends who support me and encourage me whenever I was facing challenges. Without you I won't be able to make it! Love you guys so much!

Most importantly thank my parents, for everything!

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# **Thanks!**

Wen Tang